THE CHALLENGE OF AIDS:

A NOVA SCOTIAN RESPONSE

Report of the Nova Scotia Task Force on AIDS

Nova Scotia
Province of
Nova Scotia

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Background Documentation

September 1988

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What the Provinces are Doing

A Background Report for the Nova Scotia Task Force on AIDS

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What the Provinces are Doing

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Introduction

The survey which follows relates to policies and work being carried out in other Canadian provinces and territories.

The purpose of the survey was to produce a document which would highlight provincial responses to four basic categories of questions related to the handling of AIDS issues. These were concerned with:

Medical Care
Testing and Surveillance
The Workplace
Public Awareness and Education

Methodology

The survey was carried out through telephone interviews with a number of representatives from each province and territory. The interview followed guidelines and questions taken from a prepared questionnaire.

Some comments about the results of the survey may be useful in assessing the information as it has been presented. In particular, it was limited by pressure of time on the part of both the people being interviewed and the person undertaking the interviewing. Key personnel were away, or it was difficult to reach referrals who might have more in-depth knowledge about some of the questions. Some of the questions were not applicable to all regions, because the number of AIDS cases varied greatly in different areas, and so the means of dealing with AIDS locally also had very variable applications. On the part of the interviewer, there was sometimes an ignorance of local anomalies, programs, and political situations which made it surprisingly difficult to envisage accurately what was being described, and to communicate effectively within the available time span and through the entirely oral methods of a telephone survey. (This might, however, provide a useful insight into the difficulties of educating the general public, and the fact that nothing can be assumed!)

The Questions Involved

The first questions were concerned with medical care. For example, what medical facilities are available to people with AIDS/HIV infection? Can they be admitted to any hospital, and to any wards, or are there designated ones? Are there any restrictions about this? Are there separate out-patient, dental or psychiatric units? Have universal precautions (or some other kind of infection control measures) been instituted, and who makes the decisions related to this? What kind of model of medical care is there for the treatment of AIDS, and does it include alternatives and options? Is homecare, palliative care and hospice care available to PWAs, and how developed are these services regionally? How has AIDS education of staff been handled? Has it included orientation of new staff, and is there provision for on-going training of all employees besides those engaged directly in medical care? Are there policies about the employment of HIV infected individuals, or for the testing of personnel who are employed in work which would put either themselves or their patients in a higher risk category (such as, perhaps, orthopedic surgery)? Has there been concern about the maintenance of confidentiality? Medical costs were discussed from the point of view of pressures on the patient rather than on the institution or government, since a sophisticated analysis of data was out of place.

Secondly, details about methods of testing for the AIDS virus, counselling (with its many implications), and the tracing of sexual contacts were requested. Such questions included information about what policies have been formed around mandatory (or voluntary) testing for HIV infection as well as for AIDS, and whether tests are conducted on a nominal or non-nominal basis. What kind of screening and confirmatory tests are employed, and what laboratories are involved? Has there been a need to increase funding, staff or laboratory facilities to cope with the added demands? Are there ethical concerns over methods of testing, seroprevalence studies, confidentiality, counselling and contact tracing, and have guidelines been issued to make both professionals and clients aware of the personal and ethical implications of agreeing to be tested?

The third set of questions dealt with AIDS in the workplace. An attempt was made to determine whether there are policies or guidelines about the right to work or to refuse work. Are there restrictions about the kind of work a PWA/HIV infected person may undertake? Is there legal or Human Rights protection for PWAs, their associates and families against discrimination or breach of confidentiality? Are employers seeking to educate their employees about AIDS issues, and if they are, is this being handled unilaterally or with the help of government? Have guidelines been produced for employers who wish to develop internal policies about AIDS, hiring and firing practices, the position of co-workers who are reluctant to continue to work with an individual who is HIV infected? What burdens are there on employers, including the onus of maintaining a safe working environment?

Questions were also raised about what training there has been for people employed in providing emergency services, and whether they have been advised about infection control, and been provided with safety equipment (such as resuscitation mouthpieces). Have policies and guidelines been developed for such services, and also for professionals exposed to greater risk of infection, such as in funerary preparation?

Another aspect of the workforce questionnaire also involved the role of social services, in providing help for PWAs who had experienced difficulties over the loss of a job, income, housing or other social pressures related to AIDS or HIV infection and financial instability.

The fourth section of the questionnaire tried to elicit what measures have been taken in Canada to educate the general public; to determine what constitutes risky sexual behaviour and how AIDS infection may best be controlled. Descriptions of government programs were asked for (what has already taken place, what is currently in effect and what is being planned for the future). What kinds of outreach have been attempted, including the production of pamphlets, educational materials and other means of dissemination of information? To what extent has the media been involved? Is there any control over the dissemination of information, and is the correction of misinformation being addressed? Are direct and personal means of communication about AIDS concerns available to both the public and professionals (such as hotlines, infolines, individual counselling), and are some of these sorts of services offered on an anonymous basis? What are the community resources in terms of people, collated information (libraries, resource centres), and encouragement of research? Have new groups or committees been formed to respond to AIDS issues, and what has been the role of volunteers? Has AIDS education been developed for the schools, and if so to what extent are these mandatory or discretionary? Have teachers been trained specifically to talk about AIDS and in the presentation of AIDS materials, and are enriched resources both available and known to them? Has there been any attempt to reach the school drop-out and the street kid?

In addition, an effort was made to gain insight into another group of questions which focussed on special aspects of the overall questionnaire. These attempted to probe and ask for evaluation of what has been accomplished to date. Do provinces/territories have strategies in place, and, if they do, were these stop-gap measures in response to a crisis, or the result of careful long-term (or short-term) planning? In hindsight, would programs and policies have been handled differently if there was the opportunity to start again? Is there a need for revision? Have the various regional endeavours been isolationist, or has there been an attempt to achieve interprovincial and federal co-operation and communication, and to avoid the duplication of materials and efforts? Have they been achieved at great cost, in terms of either human or financial distress, or has the reverse been true?

Some General Observations about the Answers

From these sorts of questions there emerged a picture which is complementary to facts presented in the main body of the report, and they were presented without inference. From personal discussion there was an intimation that the course of the Canadian epidemic seems to be developing along somewhat different lines than the experience in the United States. Since much of the initial Canadian planning for AIDS was based on what had already been done in the U.S. this has necessitated reviewing Canadian strategies and policies in a fresh light. At this time, recent data suggests that the rate of new infection in Canada is flattening out, and the reasons for this are open to a number of interpretations and hypothetical projections. This has intensified interest in surveillance methods and the collection of data, but has at the same time deepened concerns about the issues around confidentiality. Ethical and legal implications of AIDS policies and the complexities of decision making with regard to these has stimulated much discussion and agonizing over traditional concepts and values. Another major theme which was brought out in discussion was a fear of complacency and attitudes of personal invulnerability on the part of some sectors of the general public, and an urgent need to repeatedly re-fuel respect for the deadliness of the disease, together with the awareness that at this time it can only be controlled through the exercise of individual responsibility over its transmission. To promote this information without inciting undue fear has necessitated considerable sensitivity on the part of those involved with public information and awareness programs.

Finally, there seems to have developed a growing interest in models of medical care, both from the point of view of financial planning and consideration of human need and compassion for the sick. There is seen to be a need for flexibility in this, an openness of mind to perceive untried or newly-formed directions, and to research means of medical care which would enrich the quality of life for the patient and offer a variety of options. This includes questioning the more traditional roles of hospital care, the centralization/decentralization of medical facilities, the possible extension of outpatient facilities, experimentation with new treatment and drugs, and the retention of as normal a lifestyle as is practicable in dealing with an epidemic disease.

Conclusion

As already noted, a survey of this kind requires the involvement of many people. I would like to take this opportunity to thank all those who took part for the generosity with which they gave their time and patience; for their willingness to share and send out materials; and for the thoughtfulness with which they reviewed and critiqued the draft paper. What was probably the most appreciated of all, was the sharing of warmth, commitment and enthusiasm about the tasks which had been undertaken, sometimes under the pressure of lack of time, people and financial limitations, and always under the cloud of a dreadful disease; the spirit of high morale, humour and personal challenge was genuinely uplifting.

Barbara Whitby
Halifax, September 1988

Medical Care

National

"Care of Those Infected with HIV

> "Tragically, opportunities for lessening the impact of the epidemic on those already infected with HIV are very limited. Their burden can be eased by the provision of comprehensive and continuing medical care, appropriate housing, and psycho-social support. At one end of the spectrum of those involved in care are friends and family who give essential comfort; in the middle are more specialized personnel such as nurses and laboratory technologists; and at the other end are highly specialized personnel such as physicians and dentists.
>
> Because health-care resources are limited, their allocation to AIDS patients – many of whom eventually require intensive care – creates ethical dilemmas at the institutional and societal levels. Decisions for AIDS patients must be made in the same ethical context as they would be for other patients, bearing in mind the primacy of the dignity and worth of the patient and the desirability of respecting autonomous decisions.
>
> The Canadian health-care system, good though it is, was not designed to cope with the current AIDS epidemic that is making unforeseen and increasingly heavy demands upon it. AIDS is now a steadily growing, labour-intensive, socially disruptive health-care challenge.
>
> It is estimated that on any given day there are 100 to 150 AIDS patients in hospital in Canada. Over 80% of these patients are cared for in Montreal, Toronto and Vancouver. Almost all hospitalized AIDS patients are in teaching hospitals, and few hospitals, if any, have developed clear policies for admitting and treating them. At present there are only 18 beds officially assigned to AIDS patients in the entire country: these beds are in St. Paul's Hospital in Vancouver.
>
> Provision for the care of AIDS patients has necessitated the diversion of already sharply restricted funds, as well as space and facilities, from other medical specialty areas. As a result the resources of many hospitals are strained and the physicians responsible for AIDS care are severely overworked. . . ."
>
> "The major cost of providing care is staffing, both inside and outside of hospitals. Large numbers of trained personnel are required in some areas of care. For example, the counselling of persons tested for HIV antibodies requires that services be available in doctors' offices, hospital outpatient departments, sexually transmitted disease clinics, and alternative test sites.
>
> To pursue this example, a rough estimate can be made of the number of counsellors required for the 30,000 persons in Canada who may present themselves for testing and who may be found to be HIV seropositive. In addition, for each seropositive person there are at least two friends or family members who require counselling and follow-up. We estimate that the equivalent of 945 full-time counsellors (260 medical/paramedical and 685 psycho-social) are needed for individual counselling of the infected. In addition there are many uninfected persons who ask for testing and counselling.
>
> A background paper published as part of this study proposes a system of care for those infected with HIV. Such a system would be based for the most part on facilities in and around university hospitals, particularly in Vancouver, Toronto and Montreal. It would comprise dedicated AIDS

inpatient and outpatient facilities staffed by multidisciplinary teams, screening and counselling clinics, community care facilities (at home and in extended-care and terminal-care facilities), and in the larger cities an AIDS centre, which in most instances would be under the aegis of a university. The AIDS centres would coordinate education, research, and patient care and would provide liaison with municipal, provincial, and federal governments.

Finally, it is emphasized that the proposed system of care will require new resources and the provision of new funds rather than the reallocation of funds from existing budgets. Ad hoc care for AIDS patients is no longer defensible."

Recommendations were:

"4. We recommend that the federal and provincial governments cooperate in the establishment of a system for the care of those infected with HIV, along the lines of the system proposed in a background paper to this Report.

5. We recommend that a survey be undertaken immediately on a provincial or regional basis to determine the human and institutional resource requirements for the proposed system of care of those infected with HIV."

(From *AIDS: A Perspective for Canadians*, Summary Report and Recommendations, Royal Society of Canada, April 1988.)

Alberta

The Federal Centre for AIDS statistics for June 13, 1988 gives the figure for AIDS cases as a total of 100, 59 of whom have died.

Model of Care

There is no separate model of medical care for AIDS.

Private Practitioners

Private physicians undertake on-going care, but refer patients to specialists as this is needed. The greatest number of AIDS patients are treated in Edmonton and Calgary.

STD Clinics

STD Clinics make confidential HIV testing and counselling available in Edmonton and Calgary. Ambulatory HIV infected patients who do not require hospitalization can be monitored through STD clinics, and protocols have been developed for follow-up procedures.

Specialists

The majority of AIDS specialists practice in the Infectious Disease Clinics in Edmonton and Calgary and the two university hospitals, the University Hospital of Alberta in Edmonton and the Foothills Hospital in Calgary.

Wards and Units

All hospitals would admit people with AIDS, but not all are called to do so, and none has refused yet. There are very few cases in rural areas, and about eighty-four percent of cases have been homosexual from the major urban centres. Some patients who were placed in rural hospitals were transferred almost immediately to the care of specialist facilities as they were so acutely ill.

There are no designated wards for AIDS, people with AIDS are integrated into the general hospital facilities.

Home Community

In the long run the government is encouraging routine care in the home community wherever possible.

Out-Patients

There are no separate out-patient facilities for AIDS, and people with AIDS use the existing services.

Infection Control

The province is adopting universal blood and body fluids precautions. There has been no legislation, but universal precautions are being strongly encouraged. The government avoids interference, and hospitals have their independent boards and their own guidelines.

The Alberta Hospital Association has a set of guidelines which is being updated. It is working in close co-operation with the AIDS Workplace Consultant, the National Laboratory Centres for Disease Control, and the provincial AIDS program.

Policies for Health Care Workers

There is no policy for HIV infected health care workers. Employers are encouraged to treat employees as able to work unless it is apparent that they are no longer capable of doing so. Normally the person's HIV status would not be known in any case.

There is no policy requiring hospital personnel such as surgeons to be tested for the HIV virus. The government is discouraging random screening, and is following Sullivan and Gilmore's recommendations. Occupational Health Division is issuing a set of bulletins directed to Health Care workers. The National Needlestick Protocol is also encouraged.

Confidentiality

The regulations governing confidentiality depend on the situation and who is concerned. Civil servants sign a declaration of confidentiality, and people in networks have their own ethical guidelines and rulings.

The principle of maintaining utmost confidentiality is endorsed by the government.

Seropositivity is not reportable to Public Health authorities.

Training and Information on AIDS

Each hospital has its own policies for training, and so there are many variants.

The Department of Community and Occupational Health developed education packages for health-care professionals. The STD Education Unit staff provide educational sessions.

In 1986, all health units were provided with AIDS information kits to distribute to all local physicians. The government's package "Information for Health Care Providers on the HIV Antibody Test" and its accompanying three pamphlets on testing for patients has just been re-issued.

A strong aspect of Alberta's three year plan is to conduct education programmes for physicians and other health care workers; to increase knowledge of transmission of AIDS and infection control, and to foster awareness of psycho-social issues related to AIDS.

British Columbia

According to the Federal Centre for AIDS statistics for June 13, 1988, there have been a total of 368 people with AIDS, 192 of whom have died.

Model of Care

There is not a totally separate model for the medical treatment of AIDS in British Columbia, but there are separate facilities. There is a hospital clinic for out-patients at St. Paul's, Vancouver: a Dental Clinic at Vancouver General Hospital, and thirdly, integrated treatment which includes a nursing home-visits programme, home care, and admittance to any hospital.

Private Practitioners

Private practitioners provide on-going care, but refer patients with AIDS to specialists treatment as necessary.

Specialists

Specialist facilities tend to be at the large hospitals.

Wards and Units

All hospitals, including rural ones, would admit people with AIDS, but some hospitals prefer to make referrals to St. Paul's in Vancouver. This would be an entirely local decision, some are uncomfortable at handling AIDS.

There are not designated wards, people with AIDS go into a general ward, but they are given a private room. This is because AIDS needs a high level of nursing care, and blood and body fluids precautions must be taken. It can be highly infectious. Instruments have to be well sterilized, and certain procedures, such as examination with an endoscope or sigmoidoscope, are often left until towards the end of the day for that reason.

Out-Patients

There is an out-patient's Infectious Disease Clinic at St. Paul's hospital in Vancouver, and a special study of AZT is being undertaken through it.

Infection Control

The government cannot direct hospitals to use universal safety precautions, but it strongly recommends them to do so. Each hospital makes its own decisions and follows its own policies, but most are moving towards universal blood and body fluids precautions. The government has sent handbooks to all hospitals making recommendations about this.

Policies for Health Care Workers

Each hospital has its own policy about the employment of workers who are HIV seropositive. It is not known what individual hospitals may be doing about requiring hospital personnel, such as surgeons, to be tested for the AIDS virus, for the same reason, but there have been no complaints. The government does not support screening other than for donors.

Confidentiality

There is no new legislation dealing specifically about confidentiality with reference to AIDS. Medical care comes under the Human Rights Code.

It is being emphasized to hospital staff that medical records are confidential.

Anyone dealing with testing is being reminded of the confidentiality requirements.

There is no written legal policy about the "need to know", but the Canadian Medical Association ruled that information can be released through a physician to someone who is considered to be at risk. (For example, the spouse of a bi-sexual HIV seropositive person).

It is very difficult to protect the confidentiality of people who live in isolated areas, both from the hospital's end and the physician's perspective. The Department of Health emphasizes the need for this, and comprises all employees, including secretaries, in its recommendations. Because of the difficulty of maintaining privacy in a small place, it is suggested that people who wish to be tested should go through the Health Unit or Vancouver.

Training and Information

Each hospital makes its own decisions about training and orientation programmes. The larger hospitals have on-going AIDS education for their workers.

Ministry of Health employees participated in numerous workshops and hospital presentations on AIDS. All Health Units received a copy of an AIDS education video to be used for public presentations.

Pamphlets

Pamphlets that have been produced include:

"AIDS: Important Information for Health Care Providers", with specific sections on precautions for health-care and laboratory personnel, and "Information for Physicians on AIDS and the Human Immunodeficiency Virus (HIV) Antibody Testing", which gives extensive information on the etiology, transmission, clinical manifestations, treatment and prevention of AIDS; Red Cross screening, antibody testing; the importance of, and necessary content for, pre-test and post-test counselling, and issues regarding confidentiality.

Manitoba

There have been 26 cases of AIDS as of June 13, 1988; 14 people have now died.

Model of Care

There is no separate model of medical care for persons with AIDS; they are integrated into the general health care structure.

Private Practitioners

Private practitioners provide on-going care, making referrals to specialists if this is needed.

Specialists

Infectious disease specialists are located in the tertiary care hospitals in Winnipeg, and most PWA's are referred there.

Wards and Units

No special wards or units have been designated for AIDS. All hospitals can admit AIDS patients, but there are two tertiary hospitals,and because the infection disease specialists are located there, people with AIDS tend to be referred there. Each provides its own regulations.

Out-Patients

There is no separate out-patients clinic. People with AIDS are seen in the Infectious Disease or Oncology clinic. The numbers do not warrant special facilities at this time, but this might be considered at a later date if this situation changes.

New Facilities

An ad hoc committee is looking at the issues of integration and co-ordination of services and care for persons with HIV infection. This includes home care, community care, and institutional care.

Policies for Health Care Workers

No special policies have been enacted about the HIV infected worker, nor are hospital personnel, such as surgeons, required to be tested for HIV infection.

Confidentiality

The Medical Care and Public Health Acts require confidentiality from both employers and employees.

There is no new legislation covering "the right to know".

Training and Information on AIDS

The Department of Health instituted in-services for public health nurses and counsellors to provide counselling and information sessions to individuals and groups on AIDS and HIV infection.

Books and Pamphlets

The Department of Health produced a booklet, "Information Update for Health Care Providers: Human Immunodeficiency Virus", and a series of "Interim Guidelines for Hospitals, Laboratories and Pathologists".

New Brunswick

There have been eight cases of AIDS altogether in New Brunswick. Two people are still living.

Model of Care

The initial treatment and on-going care is in the hands of the patient's private physician.

Specialists

Theoretically AIDS can be treated in any hospital in the province. Most cases in New Brunswick have been cared for at one of the larger regional hospitals of the province. Some have been referred on to the Victoria General Hospital in Halifax, N.S., where there are more specialized facilities.

The Stress of Travel to Specialist Facilities

Having to travel to the specialist facilities at the Victoria General Hospital in Halifax can be very tiring and expensive for AIDS patients. Although all the medical costs are assumed under the Canada Assistance Plan, accommodation, food and travel expenses have to paid for privately. Since a person infected with the AIDS virus requires constant monitoring in between bouts of acute infection there can be considerable financial hardship involved.

Extra Mural Hospitals and Home Care

People with AIDS also have the option of using the extra mural hospital services and Home Care programme offered in New Brunswick. One person has taken advantage of these.

Out-Patients

There are no special out-patient facilities for AIDS, and patients are integrated with the rest of the general public.

Infection Control

Universal precautions are being recommended for hospitals but there has been no legislation around this. Each hospital (board) is ultimately responsible for developing and implementing the infection control policy which they feel is most appropriate for their institution.

Training and Information on AIDS

Most hospitals have provided some staff educational programs around AIDS and infection control. Staff education programs are the responsibility of the individual hospital. Some hospitals, in particular the larger regional hospitals, have initiated extensive educational AIDS programs. Some other small hospitals have not yet begun to initiate any programs.

Policies for Health Care Workers

There are no special policies about the rights of an infected person to continue to work, and there are no requirements for hospital personnel such as surgeons to be tested for HIV infection.

Confidentiality

Hospital patient information is confidential, and this is legislated by the Health Act. This is being emphasized to staff who are dealing with AIDS so that they are more conscious of the serious implications of breach of confidentiality.

The Nursing Association is also reminding nursing staff to be careful about maintaining confidentiality, and that there is a clause in the Code of Ethics which can lead to a severe reprimand if this is broken.

The issue of "who needs to know" is being discussed in hospitals.

Although the name of an individual testing HIV-positive must be disclosed to the physician, at the same time the physician is encouraged to encode the name for data purposes and for the laboratory specimen.

There has been some concern that people in high risk groups may be avoiding being tested because of the worry of their names becoming known.

There are stringent guidelines at AIDS New Brunswick.

Newfoundland

There have been eight cases of AIDS in Newfoundland as of June 13, 1988, of which six have died.

Model of Care

There is no separate model of medical care for AIDS, and the government is not specifying which hospitals will treat AIDS patients.

Private Practitioners

Private physicians give on-going care and make referrals to specialists as it is necessary.

Specialists

Although all hospitals can admit AIDS patients, the Health Science Centre at St. John's is the largest tertiary care centre, and is developing a support group for AIDS within its services.

Some psychiatrists have developed a particular interest in AIDS and are available for consultation.

Wards and Units

There are no policies to designate special wards for AIDS, but PWA's are put on a separate ward in the Health Sciences Centre. This is not because they have AIDS, but because it facilitates care. People with AIDS have been treated in other hospitals too, all of which have their own arrangements.

Out-Patients

There are no special out-patient facilities for AIDS patients,they attend the regular clinic.

New Facilities

No new facilities have been planned for, except for the expanding interests of the tertiary care hospitals.

Infection Control

The government is not directing hospitals to follow universal safety precautions, but the Provincial Advisory Committee on AIDS has drawn up guidelines which have been endorsed and sent to all the major hospitals. These are recommendations only and have not been legislated.

Each hospital makes its own decisions about how it will act. The very small rural hospitals adopt measures appropriate to their own situation. Each hospital would also decide what policies would be initiated for the use and distribution of infection control kits. There has been no need to consider enforcing control or taking legislative action because so far it has been a good experience, and nothing further than recommendations have been called for.

Copies of the Canadian Disease Weekly Report Supplement, Recommendations for Prevention of HIV Transmission in Health Care Settings, Nov. 1987 Vol 1353 have been distributed to all health care institutions in the province.

Policies for Health Care Workers

There is a policy for health care workers who are HIV infected, for example, restricting them from working actively with patients if they have weeping dermititis or an immuno-suppressed condition. These have been stated in the guidelines.

Confidentiality

There are no specific policies on confidentiality regarding AIDS, though there are existing general policies which would apply to a number of situations.

This has heightened the sense of need for confidentiality in hospitals, and there is much greater care in the filling out of forms and other office procedures.

There are no "need to know" policies about HIV + status in the hospital.

Training and Information on AIDS

There is an orientation programme for new workers in major hospitals.

There is also on-going education for all health care workers, including nurses, lab technicians, dental and medical students, and all support staff such as laundry and kitchen personnel. This is done through in-services, which are repeated regularly, as necessary.

Physicians in the major tertiary care and secondary care hospitals have medical rounds and in-services on AIDS.

The Medical Association is also involved in a continuing education programme throughout the province, which takes place several times a year.

The Department of Health provides in-service education for public health field staff.

All physicians were distributed an AIDS information kit.

Northwest Territories

There has only been one person with AIDS in the NWT.

It is anticipated that people requiring tertiary or secondary level care would be medevaced South, and so the care of AIDS patients would only apply to the early or pre-diagnosis stages of sickness.

At the present time all efforts are being directed *towards preventive education programmes*.

As more people with AIDS are discovered in the NWT, local hospitals may become more involved.

The government of the Northwest Territories has provided guidelines for Health Care professionals.

Confidentiality

The government of the Northwest Territories has developed and distributed guidelines for health professionals which provide for the confidentiality of clients, and various hospitals have developed policies which articulate their position on confidentiality.

A draft policy is being drawn up and should be completed shortly.

Nova Scotia

There have been 31 cases of AIDS diagnosed in Nova Scotia up to June 1988; 12 of those persons have died. In addition, about 120 people are known to be HIV seropositive. It should also be noted that a number of persons (approximately 10) who have been diagnosed elsewhere have been treated here for AIDS but are not included in the number of 31 diagnosed.

Model of Care

There is no separate model of medical care available for people with AIDS in Nova Scotia; however, there are a number of special services available, as there are with other diseases (for example a dental clinic at Dalhousie and out-patient clinic at the Victoria General Hospital). The province has encouraged the adaptation of existing services to meet the generic health and social services needs of people who are HIV positive or who have AIDS.

Private Practitioners

Private practitioners provide on-going treatment locally for people who are HIV infected. However, if some specialist treatment becomes necessary (and this is essentially routine), they are referred to the Victoria General Hospital in Halifax, which is the largest tertiary care centre in the province.

Specialists

Almost all specialists who deal with AIDS in Nova Scotia are clustered in Halifax, and all AZT treatment is supervised from there. Although AZT may be administered elsewhere, patients living outside of Halifax usually have to travel to the city once every two weeks for a check-up. This has caused some PWAs added stress because of the difficulties over taking time off work and the financial and emotional stress of repeated travel.

Wards and Units

Since February 1983, most in-patients with AIDS have been treated on the Infectious Disease ward at the Victoria General Hospital. Patients with AIDS are nursed on the Infectious Diseases unit, and patients with other categories of HIV infection who require hospitalization for non-HIV-related conditions are nursed on the appropriate nursing floors.

To June 1988 the VG has been involved in the care of 38 in-patients with AIDS. Great care is taken to protect confidentiality. Theoretically PWAs can be treated at any hospital in the province but tend to be referred to the VG because of the specialist facilities there. PWAs from New Brunswick, PEI, Ontario and the United States have also been treated at the VG (30 from N.S., 8 from other areas). It is noted that AIDS patients have been treated in both regional and community hospitals in Nova Scotia.

While they were hospitalized, AIDS patients have required extensive consultative care, including the services of neurology, dermatology, gastroenterology, psychiatry, surgery and neurosurgery, dietetics, social services, psychology, chaplaincy and nursing. In addition, input from family practitioners and those groups associated with high risk activity have been sought in providing the best overall care for these patients.

Out-patients

There is a weekly out-patients clinic solely for people with HIV infection, at the Victoria General Hospital Infectious Diseases Clinic. There is an average of 10-15 patients visits per week (approximately 100 out-patients per annum are seen on a regular basis at varying intervals).

New Facilities

The necessity for expanding out-patient services at the VG in the near future is being discussed.

Infection Control

Each hospital forms its own policies in relation to universal blood and body fluids precautions. Some have more extensive infection control procedures than others, or may have them in place in specific areas only. In general, the potential cost of universal precautions is being assessed. The VG has adopted this in principle, but it has not been implemented. The N.S. Medical Association and the Dental Association are promoting universal precautions for practitioners' offices.

Policies for Health Care Workers

There is no provincial policy for HIV infected health care workers, and each hospital makes its own decisions, but guidelines are available from the Nova Scotia Department of Health and Fitness and have been available to hospitals. Hospital personnel, such as surgeons, are not being tested for the HIV virus. The Provincial Epidemiologist produced "Medical Guidelines for the Management of Exposure to Blood/Body Fluids" in January 1988, dealing with accidental exposure to the virus through medical procedures. In a pamphlet by the Department of Health and Fitness, "AIDS and the Workplace," infection control information is outlined for health care workers, and employers are also encouraged to treat HIV infected employees as they would any other worker, provided they are capable of performing the job, and to be sensitive to alternative employment for them at times of periodic bouts of sickness.

Confidentiality

There is no new legislation dealing specifically with confidentiality as regards AIDS. Personnel working in a hospital or clinics have to sign an affirmation of agreement to confidentiality, but the same regulations do not apply to a private physician's office. The "Medical Guidelines for HIV Screening", produced by the Provincial Epidemiologist, November 1987, stress that "Strict confidentiality is paramount. This must be understood by all those acquainted with the identity of the patient, including office personnel . . . ." (page 8).

Training and Information

Each hospital Board makes its own decisions about training and orientation about AIDS. The larger hospitals are providing in-services for physicians and all staff, including such personnel as laundry workers and kitchen staff. AIDS education is being increasingly integrated with training programs, and extra emphasis is being given to infection control.

Ontario

The Federal Centre of AIDS statistics for June 13, 1988 list Ontario as having had 698 cases of AIDS, 425 of whom have died.

Model of Care:

There is no separate model of medical care for people infected with the AIDS virus in Ontario, and there has been a conscious effort to integrate AIDS treatment with the existing facilities.

Private Practitioners

Private practitioners give on-going care, making referral to specialists as necessary.

Decentralization of Care

In general, all AIDS care is decentralized. The 43 Health Units have been financed to meet the needs, and the Ministry of Health monitors the AIDS cases, but only as one of many other types of diseases.

There are 11 community-based groups, chiefly in the large cities, who are organized to respond to the care of AIDS patients at a local level.

Specialists

In actuality, people with AIDS tend to gravitate towards the specialist facilities in the larger hospitals because the smaller hospitals often do not have the facilities or infectious disease staff. In Metropolitan Toronto there are 19 different hospitals where cases of AIDS have been diagnosed. Teaching hospitals tend to be clustered in this city.

Wards and Units:

There are no designated wards for AIDS patients, but some hospitals do have separate wards because it is more convenient to have them. Some hospitals treat AIDS patients on the general ward, but there is a mix of practices, and each hospital has its own policies and procedures. PWA's are often treated in the infectious disease units.

Out-Patients

There is a need to increase out-patient facilities for AIDS, and several hospitals were given extra funding towards this in the Spring of 1988. (Toronto General, Sunnybrook Medical Centre, St. Michael's Hospital, Wellesley Hospital, The Hospital for Sick Children). AIDS out-patients clinics have specialized staff who will promote comprehensive medical, nursing, psycho-social care and follow-up for people with AIDS and AIDS-related illnesses.

The most acute need is possibly to incorporate out-patient care within the smaller communities. Recently the needs of people who are HIV infected were monitored. The three areas of nursing, medical and psycho-social out-patient needs were studied, and the psycho-social needs heavily outweighed the others.

New Facilities

New facilities are especially needed for out-patients in the community.

Infection Control

There is no formal legislation, but there is an informal direction towards universal safety precautions for AIDS, and infection control staff strongly favour this.

Each hospital makes its own decisions and implements its own routines about infection control. Any enforcement of these measures would come from within the institution itself.

Policies for Health Care Workers

There is no official policy for health care workers who are HIV infected, although the Provincial Advisory Committee has prepared a guideline saying that an employee who is able to work may continue to do so. Some individual hospitals have made statements that any employee of HIV + status must declare this to their working superior in order that there can be some control over their area of work. This is a Human Rights issue, in that the law is very clear about the rights of an individual. No one may be forced to disclose personal information of this sort. At the same time, because HIV + is reportable, all reported cases are monitored by the Medical Officer of Health, so that the MOH Medical Officer of Health is ultimately responsible for controlling decisions about any given individual's physical or mental state. Hospitals are not firing employees over this issue, simply asking the HIV + to report their status.

There is no policy requiring hospital personnel, such as surgeons to be tested for AIDS. The Provincial Advisory Commission is looking into this question. At present the opinion is that there is no extraordinary risk attached to having people with AIDS working under normal conditions. Under the Health Protection and Promotion Act, the Human Rights Act and the Occupational Health & Safety Act it is forbidden to discriminate against an employee, but at the same time the employer has the responsibility to see that the workplace is safe. An employee could file a grievance if it could be proved that there was not adequate protection. There are rules about what should be provided, and these can be compared with what has in fact been provided. This whole issue is quite controversial.

Confidentiality

Confidentiality concerning AIDS is legislated under the Health Protection and Promotion Act, the Human Rights Code and the Occupational Health and Safety Act.

It is legislated that no person shall disclose either the name or any other information about an AIDS patient or someone who is HIV seropositive.

There are a few possible exceptions. Information may be disclosed with the consent of the individual concerned (but this can not be required). Under certain circumstances disclosure may be required in a Court of law, and, thirdly, the Public Health Administration may be able to tell the spouse of an HIV infected person about their status, but this would necessitate special legal orders.

The "right to know" is closely restricted.

Training and Information on AIDS

The Ontario Medical Association has set up a Task Force to look at the informal teaching of physicians.

The Provincial Advisory Committee has been involved with the training of health care professionals. Ongoing training has been provided in all the major hospitals, and this includes training for nurses and support staff such as housekeeping and laundry personnel.

A Speaker's Referral Service has been very active in the education of a wide number of groups, and the Health Units have also been financed to provide AIDS education.

Evaluation

The Ministry of Health is attempting to develop an instrument to evaluate what services and teaching programmes are being offered, and to what degrees they are being utilized. This is still at the early stages, but it is slowly becoming organized.

Documents, Fact Sheets and Information Produced

The Ontario Public Education Panel on AIDS produced a document or guidelines, making recommendations to the Ministry of Health.

The Ministry of Health, in conjunction with the Ontario Public Education Panel on AIDS, produced a series of Fact sheets, among them "AIDS and Health Care Workers", and also two booklets for professionals. "AIDS and HIV infection: Psychological Issues and Information for Professionals", and "Understanding AIDS and HIV Infection: Information for Hospitals and Health Professionals".

Prince Edward Island

There have been two patients with AIDS. One of these has died.

Medical Care

There is no separate medical care model for AIDS in PEI.

Private Practitioners

Private practitioners give on-going care, and make referrals to specialists as necessary. The current patient goes back and forth to Halifax in Nova Scotia, and his own practitioner does the follow-up care.

Specialists

Patients are sent to Halifax for specialist treatment.

Wards and Units

No hospitals have been designated specially for AIDS care, and if a patient needed hospitalization it would probably be provided by the hospital nearest to where he lived, unless it was necessary to go to the specialist facilities in Halifax.

There are no separate facilities for AIDS, the patient would be admitted to the general ward.

Out-Patients

There are no special out-patient facilities for AIDS, and treatment is integrated within the existing services.

New Facilities

No new facilities have been necessary for AIDS care.

Infection Control

The Province of PEI has adopted universal blood and body fluids precautions, and the Queen Elizabeth Hospital is working with the smaller hospitals to discuss a universal protocol for this.

Each hospital makes its own decisions and policies about infection control kits, and where they should be made available or placed.

Policies for Health Care Workers

The Department of Health is not aware of any policy to restrict a person who is HIV infected from working in a hospital, but each hospital is free to make its own decisions, and the specifics would not be known unless it became an issue.

There have been no new policies about work practices. Hospital personnel, such as surgeons, are not required to be tested for the HIV virus, and there has been no mention that the Medical Association has discussed this possibility.

Confidentiality

There is general legislation which would probably cover the requirement to maintain confidentiality, and which would cover hospital and civil service employees.

Training and Information on AIDS

There is no broad training across the province, each hospital decides for itself what training it will implement. The Task Force on AIDS will be considering this, but they have not reported back yet. The PEI Medical Association has not done anything about this issue yet, but there may be more pressure on them to do so if more cases develop.

Quebec

Federal Centre for AIDS statistics for June 13, 1988 show 529 cases in total for Quebec, and 275 deaths

Model of Care

There is no separate medical model of care for people with AIDS in Quebec.

Private Practitioners

The general practitioner usually handles the early stages of the disease, but AIDS seems to be becoming a specialist disease.

Specialists

There are three specialist prevention and screening centres, "Equipes de Prevention et Depistage," one in Quebec City and two in Montreal. There are many professionals involved in each team or network, including general practitioners, nurses, and social workers, and referrals are made to specialists as appropriate.

In Montreal, one of the centres is Anglophone and the other Francophone, and other language groups can also be handled through the network.

All three teams provide for anonymous testing.

Wards and Units

People with AIDS may be admitted to any hospital, and they would go on the general ward.

Out-Patients

There are no out-patients facilities specifically for AIDS patients. They are seen at the Infectious Disease Out-patients, and their care is integrated with the usual services offered the general public.

New Facilities

Additional facilities are being planned for the near future, but it has not yet been decided what direction to take. The Working Group on AIDS is expected to be making its recommendations in August 1988, including issues related to hospitals (both external and internal concerns); private physicians; interim care; convalescent homes, and facilities for the terminally ill.

Infection Control

The Department of Health and Welfare published a short paper suggesting general measures for hospitals to follow, and asking each of them to prepare a policy. There have been no new government policies to try to enforce infection control precautions for AIDS. Any decision of this kind would be the responsibility of each hospital. All hospitals have the freedom to form their own regulations.

Policies for Health Care Workers

There is not a policy to restrict hospital care workers who are HIV infected from working as far as is known, but this would be a private matter within each hospital, and would only become public knowledge if there was a complaint. The government's position is that they may continue to work until they become too ill to do so effectively.

Hospital personnel such as surgeons are not being tested for the AIDS virus. This issue has recently been under consideration, and it was decided not to do it.

Confidentiality

There are new policies in that the identity of the person with AIDS or who is HIV infected are protected by the use of a number instead of a name. All reporting of AIDS cases must be anonymous, and the law does not allow active tracing of sexual contacts or the compulsory treatment of persons with AIDS. These are legislated under the Quebec Charter of Rights, the Public Health Protection Act and the Health and Social Services Act.

Physicians informing a third party of the danger of AIDS infection from an individual may risk a breach of confidentiality suit, but it might be defended as a "necessity", and argued as a case of negligence versus disclosure. There is yet a written legal opinion in Canada about this. ("AIDS – A Teacher's Manual, Protestant School Board of Montreal").

Training and Information on AIDS

Special training for health care workers, especially within the hospital system, is just beginning to be developed, but this is still at a very early stage of planning. When it is put into effect, it will include AIDS orientation and on-going education for all hospital personnel, from physicians and nurses to all health care workers, laundry and kitchen staff.

Saskatchewan

As of June 13, 1988, there have been 22 people diagnosed with AIDS, of which 16 have died, and 103 HIV/antibody positive laboratory results.

Model of Care

There is no separate model of medical care for AIDS. All rural hospitals could treat people with AIDS, however physicians refer cases to a specialist facility when necessary.

Private Practitioners

Private practitioners oversee treatment but make referrals to specialists as needed.

Specialists

There are two major specialists. One is an infectious diseases specialist at the University Hospital of Saskatoon. There is also a research centre there.

The other specialist is a clinical haematologist at the Plains Health Centre in Regina.

Wards and Units

There are no designated wards or units specifically for people with AIDS.

Out-Patients

There are no special out-patient facilities for AIDS. Physicians see their patients at certain hours which have been designated at out-patients for that doctor's clinic.

New Facilities

It has not been necessary to plan for new facilities for AIDS at this time.

Infection Control

The government is not directing hospitals to follow universal blood and body fluids precautions; each hospital has an established policy regarding infection precautions. However, there is a gradual adoption of universal guidelines taking place.

Infection control kits are on the supply carts on every ward at the base hospitals.

Policies for Health Care Workers

There is a policy for health care workers who are HIV/antibody positive. Since 1985, the government has encouraged use of the NACAIDS guidelines which state that anyone who is HIV infected may continue to work as long as he or she is capable, since there is no risk of transmitting the disease through normal work contact.

Hospital personnel, such as surgeons, are not routinely tested.

Confidentiality

There has been no new legislation to protect confidentiality. Each profession has ethical requirements, and there is general legislation which covers all communicable diseases.

Issues around the "Right to Know" question are currently being discussed. The present position is that "No one will be informed until they need to know".

Training and Information on AIDS

In-services have been provided by the Department of Health for public health nurses and counsellors.

Each hospital has an orientation program for new workers. Most often it is a one-hour session on infection control, which includes thirty minutes discussion on AIDS and HIV infection. At the University Hospital, Saskatoon, this is provided for residents, new medical students, and all support staff such as laundry and kitchen personnel. It is part of the staff development program, and takes place once a month, (or to meet staff needs). Each new group of workers receives this training as they are hired.

Information and Guidelines

A series of pamphlets for physicians, health care workers and laboratory personnel have been produced and distributed.

Yukon

There has only been one diagnosed case of AIDS in the Yukon, and he was diagnosed in British Columbia and returned home during the first week of May, so in one sense there has not been a case in the community yet.

There have been discussions about what may need to be done in the future, but it has not been applicable yet.

Wards and Units

There are no designated wards for AIDS patients. Anyone who is very ill would be evacuated to Edmonton or Vancouver if treatment was available there that could not be provided in the Yukon.

Ventilated isolation rooms on the medical ward would probably be used for AIDS patients, not so much to isolate the patient from others as to protect someone who would be acutely sick from becoming infected by others.

Out-Patients

People with AIDS needing out-patient facilities would be treated in the Emergency Department with the general public, there would be no need for differentiation.

Infection Control

Guidelines for handling infection are the same as for Hepatitis B and there are routine procedures which are already in place. There are infection instructions provided throughout the hospital, and there is an infection control nurse.

There is no legislation to control safety measures.

Policies for Health Care Workers

Medical Services employees follow the recommendations of Canada Disease Weekly Report Nov. 1987, Vol. 1353. No hospital personnel, such as surgeons,are being tested for AIDS. All testing is voluntary, and no testing would be done without that person's consent.

Confidentiality

There is no new legislation for AIDS, although there has been some discussion about revising the Public Health legislation, (in what way has not been released). The Communicable Disease Officer in Whitehorse keeps a very tight control over all information related to testing. Everyone tested goes through her clinic, and she gives the results by phone. She lets no information out, even to doctors, without the patient's consent. If she is away, no tests are done until she returns.

The Royal Society of Canada's recommendations have just been received and will be studied and discussed.

Training and Information on AIDS

The Communicable Disease Officer does an orientation programme for new workers with the Community Health nurses and Hospital Infection Control. The programme includes both information and films, and involves all hospital health workers, laundry and kitchen personnel. The programme will be part of continuing education, but it has only just started. There is a quick turnover of staff to deal with; many people come to the North but do not stay for a long period of time.

Summary

No Separate Model of Medical Care for AIDS

All provinces/territories.

Separate Outpatient Clinic for AIDS

British Columbia, Nova Scotia, Ontario.

Extra Mural Hospital Facilities for PWAs

New Brunswick.

No Special Policy for Health Care Workers Concerning AIDS

All provinces/territories (except for limited applications in Newfoundland).

No Government Policy to Test Hospital Personnel for HIV +

All provinces/territories.

No Government Legislation Requiring Universal Blood and Body Fluids Precautions

All provinces/territories.

Hospitals Decide Own AIDS Policies

All provinces/territories.

No New Legislation Regarding Confidentiality re AIDS

All provinces/territories.

AIDS Specialist Facilities are Largely Clustered as Follows:

Alberta : Edmonton and Calgary
B.C. : Vancouver and large regional hospitals
Manitoba : Winnipeg
N.B. : Large regional hospitals or referred to Halifax, N.S.
Nfld. : St. John's
NWT : Seriously ill patients evacuated south
N.S. : Halifax and large regional hospitals
Ontario : Toronto and large regional hospitals
P.E.I. : Referred to Halifax, N.S.

Quebec : Quebec and Montreal
Saskatchewan : Regina and Saskatoon
Yukon : Seriously ill patients are evacuated to Edmonton (Alta.) and Vancouver (B.C.)

Home Care

Overview

"The Positive Aspect of AIDS

Within AIDS lies the potential for positive change in our society, for profound and far-reaching effects on health care and social services. Compassion, multidisciplinary cooperation, volunteerism, self-help and selflessness—these are the individual and collective values for which AIDS could be the catalyst. We believe that all this is possible, provided we are able to rise above our own prejudices, fears, value judgments and personal anxieties. . . ."

"Canada boasts about its health care system with its universal access to care. Given our already burdened services and the moral and ethical reactions to this disease, AIDS forces us to examine the sincerity of our intentions and to ask to what extent we are committed to maintaining human integrity. . . ."

"What is needed is a carefully integrated network of care comprised of both community-based and institutional services. If persons with AIDS and their loved ones are to receive high quality care, then they must be able to receive what they require, when they require it, in the most appropriate location. Needless to say, such a network does not magically fall into place. Rather, it takes considerable thought, planning, cooperation and hard work to achieve.

Persons with AIDS certainly require medical services, but our research indicates that there is also an equal, and in some instances a greater, need for what are usually thought of as social services. We learned that it was necessary to achieve a balance between the medical and social dimensions of care. We were told many times that this is frequently an issue when funding allocations are made, that is, social dimensions are generally funded poorly. Failure to provide adequate social service support affects not only the person with AIDS but the caregivers as well. Where social services are lacking, medical and nursing staff often attempt to provide social service support in addition to their other caregiving responsibilities, resulting in staff "burn-out."

In addition to the loved ones, the caregivers of persons with AIDS may also include other professionals and volunteers. Many examples of strong, well-organized community volunteer groups exist, and their contribution to the delivery of care is well-documented. Both professionals and volunteers have appropriate roles to play, and a strong care team can emerge if their roles are clearly identified and if they work together. . . ."

"2.3.2 Care Delivery

Our research showed that the decision as to the type and location of care should be jointly shared by the person with AIDS, the caregivers and the family. We also learned that the availability of different care options is of great importance. For example, it is highly desirable for persons with AIDS who wish to remain in their homes to do so. In the course of our site visits, we discovered many innovative approaches to providing care in the home, and it is clear that quality care for persons with AIDS can be provided in the home, if there is the will and determination and the resources to provide it. . . ."

"3. **Home Component**

To die at home is comforting to most people, providing sufficient help is present. Hospice programs support wherever possible death at home through a variety of services. These services are often contracted with or even based in present home health services. Further, death may not be possible at home, but "home" can be created in facilities of care. This component provides types of supports which recognize and enhance home wherever that may be. . . ."

"We do know from our survey that expensive institutional care is now being used because there is no alternative service to be had – not because the person requires or prefers institutional care. We also know from our survey and from our site visits that expensive hospital care is now being used when less intensive and less expensive institutional care, such as nursing home care, would be more appropriate.

Of particular relevance to the terminal stage of illness is the fact that many persons with AIDS would prefer to die at home, but the necessary services to facilitate this are not available. Needless to say, these dying persons also occupy expensive hospital beds because no other alternatives are available.

Our site visits and survey led us to conclude that the study of many of these cost issues must begin now so that as the number of AIDS cases increase, the allocation of our scarce health care resources will be efficient, effective and will result in quality care to persons with AIDS and their loved ones.

(8) We believe that a national policy direction is essential to the development of a universally equitable and accessible system of care for all persons with AIDS and their loved ones.

> We RECOMMEND that a national policy for the care of persons with AIDS and their families be developed by Health and Welfare Canada to ensure a comprehensive approach to AIDS care that is consistent with the Canadian principle of universal access to health care."

(Excerpts from "Caring Together: The Report of the Expert Working Group on Integrated Palliative Care for Persons with AIDS" to Health and Welfare Canada, December 1987.)

Alberta

Services

Alberta provides Home Care for people with AIDS. There is a Home Care co-ordinator in each Health Unit.

There are 27 Health Units. The Central government has an Advisory Unit to Home Care programs, and each program is run separately.

Doctors:

Physicians are not provided under the Home Care program. Patients use their own doctors, and these private practitioners are reimbursed through the Hospitals and Medical Care Insurance Plan (Alberta Health Care).

The following services are included:

- Nurses
- Social workers (when necessary)
- Occupational therapists
- Homemakers and support services
- Physiotherapists (in Edmonton and Calgary)

Physiotherapists are provided under a different arrangement in rural areas.

Child care is provided by Social Services.

Medical Equipment

There is an extremely wide range of medical equipment available, provided through the Alberta Aids to Daily Living plan.

Costs

There is a sliding scale fee for some of the services, a Means Test for others.

The Family, and Respite Care

The family cannot be paid for providing home care.

Respite care can be provided. The care givers make it known what services are available, and arrange to call in agencies to meet the needs as appropriate. There are no psychologists on staff.

Advertising of services

Advertising is promoted through the individual Home Care service, which makes its local community aware of what it has to offer. Home Care programs are also advertised in physician's offices, as the recipient must be under a physician's care.

British Columbia

Services

Statistics show that between April 1987 and March 1988, 65 people with AIDS were treated in the Home Care program.

The Continuing Care Division funded by the Provincial Ministry of Health, includes visiting Home Care Nursing and Rehabilitation Therapy services, Long Term Care (L.T.C.) Home Support services, and L.T.C. Residential Facility care. These services aim to meet the needs of people requiring care or assistance to maintain themselves in their home setting, and to provide home-like care in a residential facility when independent living is no longer feasible.

Two manuals were produced: "Caring for People with AIDS in the Community" for Community Nurses (Vancouver Health Department with B.C. Ministry of Health Continuing Care

Division), and "Caring for People with HIV in the Community, a Handbook for Caregivers" (City of Vancouver Health Department).

Doctors:

Patients remain under the care of their own physician.

The following services are included:

Home Care
- Home care nursing and rehabilitation assessment and treatment.

Long Term Home Care Support
- visiting long term care case manager
- home support services
- adult day care services
- short stay assessment and treatment

Long Term Care Residential Facility
- Long term care case manager

Since AIDS is episodic, Institutional social workers will often remain involved even when the patient is not in the hospital.

Child care is provided through Social Services.

A special effort is being made to involve the clergy.

Most patients primarily require home nursing. There is some hands-on care, attending to lesions, injections or other treatment, but there is also a need to discuss referrals with patients, make clear what resources are available to them, and to establish early palliative care. This aspect would involve visits perhaps once or twice a month. Since AIDS is essentially an episodic disease, part of the nursing care technique is to be minimally present when a person is well, but as close as is needed at times of sickness.

There is a close liaison with St. Paul's hospital. Home Care professionals meet every other week with the staff of the medical wards to discuss discharge planning for AIDS patients. AIDS Vancouver, a voluntary agency, is also represented at that meeting.

All staff provide both a mix of acute and chronic care, and are trained in palliative care methods, and so all staff also deal with people with AIDS.

Medical Equipment

Medical equipment can be provided if the patient meets the criteria, or it may be necessary to purchase or rent certain supplies or equipment, such as a walker, medications or dressing supplies.

Costs

There is not a charge for professional care, but patients do pay for long-term services if they are able to. Ability to pay is assessed on income only (capital and factors like home ownership are not considered). The client pays up-front for medications, then gets 80% back later; but it takes a while to receive reimbursement. This has created individual hardship because of the stress on cash flow, and many patients have run out of unemployment insurance benefits and have depleted their savings. Costs are supplemented according to the family's or lover's abilities to pay, and according to how much care can be provided by voluntary means, and the patient also bears some of the cost for oxygen if it is needed.

There is some concern that people who choose community care over hospital care are being penalized, since hospital care is free. An "invisible hospital" along the lines of New Brunswick's extra mural hospital is being advocated. This would involve the establishment of a hospital without walls, through which people with AIDS, as well as other patients, would get some level of supplementary help as they would if they were being treated in a conventional hospital setting.

Provincial resources are mainly directed towards education. This has necessitated very close working relationships between people providing care services in order to avoid duplication of services. The result of this has been remarkable in the way the home care program has become very client-centred in its objectives. In trying to offer the client as many options as possible, territorial possessiveness has largely been relinquished, and a good working co-operation has developed between hospital, the gay community and community resources.

The Family, and Respite Care

Shift work is being considered for nursing services for respite care, but this can only be implemented if extra funding can be found. Respite care is usually provided through the patient being sent back to hospital for a time. Homemakers can also be granted extra hours, up to four hours a day (or longer, based on individual assessment). Live-in help may also be provided, but this would only apply to homemaker support.

Advertisement of services

Programs are well known, and brochures are readily available. Hospital liaison nurses facilitate discharge and advise patients of services at the same time.

Manitoba

Services

People with AIDS have been incorporated into the existing services. Since there has been no need to set up a separate stream, there is no AIDS Home Care Co-ordinator.

Interim guidelines have been produced for home care, entitled "Home Care Providers and Long-Term facilities."

Housing

There has been a special interest in working with a voluntary agency to provide housing. The voluntary agency could, for example, look after the finding of housing (either within families who would provide care for PWAs or in apartments etc.) and the government would provide the funding.

The following services are included:

- Nurses
- Social workers
- Physiotherapists

Occupational therapists
Homemakers and Home Care Attendants

Child care is provided through Community Services.

In-services have been held for home care workers including nursing staff.

Medical Equipment

Large equipment such as beds can be provided, and other equipment is also available.

Costs

There is no charge for Home Care in Manitoba. It is a province-wide program.

The Family, and Respite Care

Family members cannot be paid for providing Home Care.

Respite care can be provided. The patient may either be admitted to hospital or a nursing home, or twenty-four hour care might be arranged at home under exceptional circumstances.

Advertisement of Services

The Home Care is a well-established program, with direct links to the acute care sector; its services are familiar to both service providers and consumers.

New Brunswick

Services:

People with AIDS are integrated into the existing services. So far there has only been one PWA who has decided to use them. Because there have been so few people with the disease, there has been no need for an AIDS Home Care Co-ordinator to be appointed.

New Brunswick Department of Health and Community Services presently offers home care services under the auspices of two different programs.

First, there is the Extra Mural Hospital, which is presently being phased-in in several areas of the province and will eventually provide services across the province. This program is designed to provide short-term, acute care similar to that which might be received in hospital. A nurse will go into the home to change dressings, give injections or whatever else of this nature is necessary.

In addition, Public Health Services are continuing to provide more limited home care services to individuals who are residing in areas not yet covered by Extra Mural Hospital, principally long term care for people over 65 years of age.

Doctors:

There is no provision for a doctor's services under the program, and patients are cared for by their own practitioners.

The following services are included:

Nurses
Social workers
Physiotherapists
Occupational therapists
Home Makers and support services.

The Victorian Order of Nurses (VON) provide palliative care. Occupational therapists specialize in working with disabled children, but also undertake more general care under the Home Care Program.

AIDS New Brunswick, a volunteer agency, also provides a Buddy System for AIDS patients, and there are some professionals involved with that, but this has nothing to do with the government services.

Medical Equipment

Equipment is made available primarily through the voluntary/community sector. Equipment rental costs are included when the client is receiving services under home care. Equipment is also available to seniors through the departmental sponsored equipment (for seniors) loan program. Other equipment rental arrangements involve a sliding scale rental fee based on the income of the family.

Costs

There is a fee for Home Care services, determined on a sliding scale. Individuals receiving income assistance are also covered for equipment rental fees.

The Family and Respite Care

Families cannot be paid for providing home care.

Respite care services are provided to the chronically ill and elderly – either through the provision of intensive homemaker services or through the Nursing Home Relief Care Program – which provides services (usually to the elderly) for two weeks to four weeks at a time (usually once a year).

Palliative Care

One region of the province, Saint John, is also receiving specialized palliative home care services. This project operates under the auspices of Extra Mural Hospital (Saint John Region). Modified palliative care services are, however, available through the Extra Mural Hospital Program.

Advertisement of services

The Home Care and Extra Mural Programs are advertised through brochures, etc. However, referrals are facilitated through a physician and, therefore, the most extensive form of advertisement is through information programs provided to physicians, hospital nursing and social work staff and public health nursing staff. Similar methods are also incorporated into the advertising of the other services described above.

Newfoundland

Services

The number of AIDS cases in Newfoundland has been so small that it has not been appropriate to consider a Home Care Co-ordinator, special programs or policies for people with AIDS. Contingency plans have been discussed, however. (Eight cases)

There is not a universal Home Care program in the province, but in many areas of the province home maker, home support and medical supplies are available through the home care program.

Doctors:

Patients are cared for by their own doctors; there is no physician support particular to Home Care.

The following services are included:

Nurses
Home Makers and personal support services.

The program is still evolving, and specialties have not been worked out yet. The services of physiotherapists or occupational therapists are not included. Social workers come under a regional program, and are available through the Hospital Social Services Support program.

Home Makers and Support Services would be supplied for people with AIDS, but there has not been a case of a person wanting to utilize these yet. If there is, special training in AIDS will be provided before the services are implemented.

Nurses would provide personal care, and would also receive AIDS orientation training.

There is no contingency for child care, but this would come under the umbrella of Social Services. Children with AIDS would receive support from the Children's Hospital (The Janeway Child Health Centre).

Medical Equipment

Medical equipment can be provided, depending on where the home is located.

Costs

There is no fee for Home Care; it is a government program.

The Family, and Respite Care

There has never been any experience of family members asking to be paid for providing home care.

The Health Sciences Centre has developed a statement about AIDS, for the provision of nursing services, physicians and social services. Respite care would probably be worked out under this if the need arose.

Advertisement of services

Home Care services have not been advertised because they are still in the initial stages of being developed, and are not yet in place as a full-time service.

Northwest Territories

Services

People with AIDS will be integrated into the existing home care services in the Northwest Territories. Fort Smith has an internal directive for AIDS, and a draft directive obtained from Manitoba has been sent to all Home Care co-ordinators pending further discussion on the AIDS issue.

There are two kinds of program involved for home care:

1) There is a co-ordinated home care service in six NWT communities.

2) Homemaker services are available in most other NWT communities and are usually contracted with the band or individual community or Hamlet Council by the Department of Social Services.

Doctors:

Anyone may make a referral, so a referral might come through a physician, nurse, the patient, family or some other source. A written order from the physician is required for certain nursing treatments. Nurses make home visits to carry out routine care and to monitor treatment. Patients continue under the care of their own private practitioner.

The following services are included:

Nurses
Home Makers and personal support services

Nurses must be licenced to practise in the Northwest Territories, and must have had several years' experience, some of which has been in the communities. They usually have experience in emergency care.

There are no social workers on staff of the program, but there is at least one social worker in each community who will provide assistance as required.

Physiotherapy and occupational therapy services are provided in locations where staff are available through a local hospital.

Some communities receive on-site rehabilitation service.

Home makers are provided in most communities where there is a home care service. They only do house cleaning chores if no members of the family can be utilized.

A feature of the home care program in the Northwest Territories is that patients may utilize one or all of the services which are offered.

A training program became available last year, so home makers may now receive formal training as well as on-the-job training.

Medical Equipment

Equipment can be borrowed through the Home Care Equipment Loan program and sometimes the nursing station or health centre.

Oxygen can be provided through nursing stations, hospitals or home care.

Costs

There are two funding sources for Home Care, the Department of Health and the Department of Social Services. The Department of Health funds the nursing services. The Department of Social Services funds home support services, homemakers, meals-on-wheels, and handyman services.

Nurses' services are an insured service through the Territory, and there is no fee for physiotherapy or occupational therapy, these are provided through Medicare.

There is a User's Fee for Home Maker's services. Fees are charged according to a patient's ability to pay, and they are on a sliding scale.

There is very rarely a charge for homemaker services, and it would be determined on the basis of a patient's income.

The Family, and Respite Care

Families cannot usually be paid for providing home care. It has happened, but under very unusual circumstances, and is an extremely rare occurrence. Whether or not the family could receive payment would be decided by Social Services.

The provision of respite care would depend on the location where the patient lived. Any of the communities near a hospital (seven) would be able to receive this service.

Advertisement of services

Brochures are available about home care services, but they are not actively advertised. Many of the communities are very small and information spreads by word of mouth.

Home Care was initiated in the Northwest Territories in 1978 and is still evolving. The most recent service was established in Baker Lake in February of 1988.

Nova Scotia

The Co-ordinated Home Care Program which is now being established on a provincial basis in Nova Scotia will provide home nursing, homemaker services, housing and volunteer services. It is anticipated that this new program of Co-ordinated Home Care will be phased in during the fall of 1988.

Under the new program, provincial guidelines and standards will be administered through the central offices of Community Services in conjunction with the Departments of Health and Fitness, Housing, and Municipal Affairs.

There will be considerable regional autonomy, and each region of the province will determine what best meets local needs and resources. Existing community-based Homemaker Services will be the backbone of the program. The Home Nursing component of the program will be co-ordinated by Community Health Nurses. Additional regional personnel requirements for adequate home nursing care will be addressed.

The current objective of the program is the co-ordination of basic service delivery. Those existing services will be added to as the need is identified and funding becomes available. Initially it will involve nursing care, Homemaker service, housing, and volunteer services where they currently exist.

Goals of the new program will be to maintain individuals in their own homes and to facilitate access to existing services. Assessment of client needs and delivery of appropriate services are seen to be crucial and the key to the success of the program.

Home Care is primarily provided for three categories of the population:

- Seniors
- Disabled
- Families at Risk

People with AIDS will not be treated differently from any other member of society, and their inclusion in the Home Care Services would depend on whether they met the criteria for admission. It is recognized that many AIDS patients may be in a state of need as AIDS is an episodic disease that may make it impossible for them to find continuing employment. Their medical condition may often put some of them in a disabled category.

The program is not designed to offer an alternative to hospital care for patients who have been given an early discharge from hospital, but it is to enable people to remain at home as long as possible.

Services

Doctors

Patients will be cared for under the direction of their family practitioner. Nurses will work in close co-operation with the family doctor in providing care for each patient.

The following services are included:

Community Health Nurses (CHN)

Contracted Nursing Services (such as Victorian Order of Nurses, Martha Home Health Care)
Certified Nursing Assistants (CNA), through the above agencies
Homemaker Services
Child Care and supervision (through Homemaker Agencies in some areas)

Homemaker Agencies

Under the new Co-ordinated Program, provincially approved Homemaker Agencies will be designated to act as the Access Agency and to co-ordinate existing (and perhaps not well known) programs and services.

Homemaker Agencies vary considerably. At present there are 48 agencies operating in all municipalities of Nova Scotia except in the town of Louisbourg. Twenty-nine programs are delivered through Municipal Social Service Departments, 8 through Children's Aid Societies, and 11 through the sponsorship of non-profit, Board-Managed Community Agencies. Numerous commercial (for profit) agencies exist throughout the province from which homemaker services may be purchased by any person desiring them.

Homemaker Agencies will be responsible for the case management of Home Care clients. Each person must be assessed for the length and type of service required, and this is evaluated regularly. It can be on a short-term basis for crisis intervention, or for longer-term maintenance.

Homemaker services may include the planning and preparation of nutritious meals, the care and supervision of children, assisting with basic personal care, light housekeeping, shopping, and budget management when requested. There may be regional differences in what is provided, according to what local agency services are available.

Nursing Care

Community Health Nurses

The assessment and plan of care of the client is developed by the assessment team. This consists of a Community Health Nurse and a Social Worker. Once a plan of care has been developed and the patient's needs and the number of nursing visits have been determined, the nursing services are contracted to provide home nursing if they are available in that region. Referrals may be made for occupational or physiotherapy services, but these are not, at present, part of the Co-ordinated Home Care Program. The role of Home Care is to make existing services easily accessible and to co-ordinate standardized services throughout the province.

Contracted Nursing Services

The Victorian Order of Nurses will be the primary provider of contracted nursing service. They provide in-home, hands-on nursing care, and their services are available through 13 branches across the province. (New offices in the areas of Bridgewater, Chester, and Lunenburg were launched in June 1988, and their services will commence in September 1988.)

The VON provide any nursing care that can be done in the home. They carry out doctor's orders with the collaboration of the family physician, or provide routine nursing care. However, although they give injections, take blood, bath patients, change dressings, remove sutures, and give nutritional counselling (among many other tasks), their primary role is to teach patients, their family, and community caregivers how to be self-reliant and independent of the professional nurse in the home, as far as this is possible.

A primary nurse is assigned to each patient. She must be a registered nurse with specific skills in community health nursing. She is responsible for a specific locality, and oversees all the patients in that area, recording case histories, making an evaluation and assessment, and setting both short-term and long-term goals for each person under her care. She may be assisted by a Certified Nursing Assistant and/or a Home Care Aide. A senior nurse or Executive Director, according to the locality, acts in a supervisory and counselling capacity and checks each patient's assessment and the goals which have been set by the primary nurse.

VON service is available, when necessary, on a 24 hour, 7 day a week basis. Most evening or night calls are made on a planned basis. All branches have staff on call and telephone answering services.

The VON is one of a number of contracted nursing services in different areas of the province which would be called upon as appropriate to the local situation.

Training in AIDS Education

Community Health Nurses have had an AIDS in-service. AIDS education is included as part of the basic infectious diseases procedures training.

The Victorian Order of Nurses has already had several people with AIDS under their care. They had an initial in-service about three years ago, and this is updated once a year, as part of a national program on AIDS education.

Homemaker Agencies have carried out AIDS education for their employees, and others have expressed similar interests. This is being reviewed by the Co-ordinator of the Provincial Home Care program (Department of Community Services) and the Director of Home Maker services.

Medical Equipment

Medical equipment is available from local business suppliers and also through volunteer agencies such as the Red Cross, the Canadian Cancer Society and the Abilities Foundation on the basis of a fee scaled to income. The volunteer agencies offer short-term equipment loans. All dressings (supplies) etc. will be provided during nursing visits. However, in between visits, the family or patient will be responsible for these materials.

Costs

Under the new Co-ordinated Home Care Program there may be a small charge for Homemaker services, based on an income test and eligibility criteria. Some agencies charge on a sliding scale.

There will be no fee charged for nursing care for patients admitted to the Co-ordinated Home Care Program Assessment and included in the care plan.

The In-Home Support Program makes cost-sharing available to municipalities who wish to provide financial assistance to families who are providing care in the home for a relative who would otherwise require to be placed in a home for special care. The Department of Community Services provides up to $400.00 per month to a caregiver. (This program is established under the Home Life Supports program of the Department of Community Services.)

Patients bear the costs of drugs unless they are on social assistance (except that AZT is provided free for PWAs under a current experimental program). The VON (Halifax) is investigating a program provided through the VON in Winnipeg.

The Family and Respite Care

A caregiver, if they are a family member, can be paid for providing homecare under the Home Life Support program. The criteria for eligibility in this program may not be applicable to a PWA who is being cared for by a non-family member as things are at present, but this is being reviewed; and the administration of the program has already been made somewhat more flexible. Some relatives of PWAs have already received assistance because of this.

Respite care can be provided currently, either by a caregiver being placed temporarily in the home, or by the patient being sent to a home for special care. What respite care will be supplied under the new program has still not been decided; regional differences will probably mean that different services will be available according to what already exists locally. Costs of alternatives are still being reviewed.

Several VON branches are investigating the feasibility of providing workers trained in gerontology for respite care. These would work in the home for four hours a day under the supervision of a primary nurse. Across Canada some branches operate Day Centres, such as the one in Vancouver, B.C., where patients are bussed to a community centre for the day. There they may receive physiotherapy, occupational therapy and other such services, be treated through special whirlpool baths, have their hair professionally tended, be entertained, and so on, and then are bussed home in the evening or collected by relatives. Such centres have been very successful, except where patients are upset by changes in their routine.

There are no plans to provide a special or separate palliative care program as part of the Co-ordinated Home Care Program at this time. Anything that exists now will continue (for example, the VON currently will provide for an evening injection, or help with, and advise on, pain control). Some recipients of these existing services may not be eligible for the Co-ordinated Home Care Program. Services to the terminally ill patient will be provided within the service limitations of the Co-ordinated Home Care Program.

Advertisement of Services

The VON have their own avenues of advertising. One is through hospital referrals. For example, the liaison nurse in the Victoria General Hospital is responsible for all nursing referrals for patients being discharged, and she tries to let them know what is available. A nurse with a similar position works at the Halifax Infirmary. VON services are advertised at the Dalhousie School of Nursing. Across Nova Scotia, staff visit community and regional hospitals regularly for liaison purposes. There is a letter and handout campaign directed towards doctors once a year, and a notice is inserted in church bulletins once a year. "VON Week" is held every January, and occasional newspaper articles are published on their activities (for example, they are a very old organization, and first became established as long ago as 1897). VON is a voluntary, non-profit organization which derives revenue from three sources: fees for service, government grants, and voluntary funds. Where the fee is paid by the client or family, it can be adjusted according to financial circumstances. No one is denied VON services because of inability to pay.

The new Co-ordinated Home Care Program is still in the process of hiring staff and finalizing details of programs. When the specifics of services in the different regions have been worked out, the program will be advertised both provincially (province-wide services) and locally (regional variants). There will be an emphasis on team work of professionals, community services available, health and housing, and the team relationship that will be essential among all contributing individuals and organizations in the delivery of Co-ordinated Home Care.

Home Care services are advertised in municipal social services offices, local hospitals and through volunteer agencies.

Ontario

Services

There are no specific policies for AIDS patients on Home Care in Ontario; the focus is on need for professional services in the home.

On March 31, 1988, there were 40 people with AIDS on Home Care, and 233 cases had been handled since 1985. A number of people with AIDS chose to die at home.

Home Care is province-wide, and there is a provincial co-ordinator but there is also local autonomy. In various parts of the province, there may be a special team to deal with AIDS (for example, in Ottawa). In Toronto, people with AIDS are mostly clustered in one area, and so by accident fall under the care of the same staff, who have become specialized teams for this reason.

Doctors:

The Ontario Home Care program is a medical model, it is not simply for support. The physician makes the referrals, gives the medical orders and provides medical supervision.

The following services are included:

Nurses
Social workers
Physiotherapists
Occupational therapists
Speech therapists
Nutritional counsellors
Homemakers and personal support services

Homemakers provide a broad range of basic nursing care. Cleaning, cooking and general care is part of this service.

It would be possible to include child care. Usually a social worker counsels the family, or refers them to a child care agency.
Services are purchased, and agencies have their own specialists.

Home Care Case Managers assess the eligibility of patients, and authorize and monitor services. If they need twenty-four hour care, it may be difficult to provide Home Care for them.

Medical Equipment

All medical equipment that is required is provided without cost to the patient.

Costs

There is no charge connected with Home Care. All patients who are eligible are guaranteed services, and this is legislated under the Health Insurance Act. Funding is through the Ministry of Health, and is approved under a yearly budget. Local agencies submit a budget, and it is provided line by line. (Funds are flowed line by line if needs increase.)

The Family, and Respite Care

Families cannot be paid for providing home care; the program provides services, not funding to families.

Services are very clinical in orientation, and geared to treatment. Family members may be given counselling if they fulfill the criteria for eligibility, but there is no on-going or bereavement counselling for them once the patient has died.

Respite care can be provided by admitting the patient to an institution.

Advertisement of Services

When the service was new, it was advertised centrally.

Local Home Care Units make their services known within their own communities, and the central office provides them with videos and pamphlets.

Prince Edward Island

Services

Home care is available to any resident of Prince Edward Island deemed to be in need. This would include people with AIDS. There have been no referrals of AIDS patients to Home Care yet.

Doctors:

Nursing referrals usually come from a physician, but they could come from family or another source if it simply involves assessment. There has to be a doctor's referral for nursing procedures such as taking blood, changing dressings, injections, catheter care, etc.

There is no physician on staff – all patients have their private doctors.

The following services are included:

Nurses
Community Support Development Worker
Occupational Therapist
Homemakers and personal support services.

Nurses work Monday to Friday (8 a.m. to 4 p.m.). There are not many referrals for evening services, and there has not been a need to schedule them regularly. Nursing services are available on weekends as well.
There is no social worker with the program.

There is a Community Support Development Worker, who performs assessments to determine needs of clients in the community, as well as assistance in accessing and setting up services and supports which will enable them to remain in the community.

A physiotherapist can be provided if the patient cannot go to hospital rehabilitation, but it is preferred that they do so if at all possible. The physiotherapist would not provide hands-on treatment, but would do an assessment and develop a program for the caregiver, and also encourage patient follow-up.

An occupational therapist is available to facilitate the client to function at the maximum level of independence in their own home.

Visiting homemakers are available to visit clients in their own homes. They provide personal support and care, such as help with dressing or mobilization, and perform basic household chores, such as vacuuming, dusting, laundry, making beds, meal preparation, and so on.

Child Care workers come under the division of Social Services.

Equipment

Medical equipment can be loaned from the Red Cross and includes such items as a hospital bed, commode chairs, and wheelchairs. Home care does not itself supply medical equipment but may approach a community volunteer group to donate an expensive piece of equipment such as an oxygen generator for a client if they could not afford to buy it themselves.

Costs

There is a fee for the homemaker service, on a sliding scale based upon income. It is a fairly generous program; for example, a person receiving OAS and GIS does not pay for the services. Financial assessment for the homemaker service is based on total monthly income. The level at which charges begin is affected by the poverty lines established by the National Council on Welfare. The services would be free to those living on low incomes. There is no fee for nursing services, but clients are responsible for providing the supplies. The Cancer Society provides some dressings and supplies to terminally-ill patients, and there is a subsidized drug plan for seniors. There is no fee for occupational therapy or physiotherapy services.

The Family, and Respite Care

Family members can sometimes be paid for providing home care. Mileage and time is a big factor, especially in rural areas, and homemaker services are contracted out. An assessment is made, and if a neighbour or person in the local community is available to provide the necessary care, they can be contracted with for so many hours. However, this is arranged with caution.

Special contracts usually continue until the time of death and are most often arranged for two to three hours a time for each terminally-ill client in need – with a maximum of eight hours per day. Longer hours can be arranged if someone needs a lot of care, but this would be for a short period of time only. If a PWA had a lover who would stay at home to provide care, consideration could be given to contract with them to provide necessary services.

The Home Care program works closely with the PEI Hospice Association, which is a privately funded voluntary agency working out of the same building, and that supports the terminally ill and the family in the home.

There is also a palliative care unit, serviced by volunteers, in the Extended Care wing. There are eight beds for the terminally ill. These are designated for any person with a terminal illness and could include people with AIDS. Policies for people with AIDS would involve particular infection control routines, but no difficulties are envisaged about including PWAs within the system.

There is a great deal of support for the family of the terminally ill. Volunteers from the Hospice Association visit regularly to talk with the primary care giver and family members, and follow up for as long as a year after the death of the patient, to give grief counselling support. There is no fee for this. The service is provided on a purely voluntary basis, but funding is raised through the community churches and "Hospice Awareness Week" to support the organization.

There is nursing liaison with the Queen Elizabeth Hospital. The nurse reviews everyone who is about to be discharged, and plans support for those requiring care following discharge. She also has regular contact with the social work department once a week. The Victoria General Hospital in Halifax can refer clients back to acute care hospitals or their own homes under home care.

Patients may be transferred from the Queen Elizabeth Hospital to the Convalescent Care Unit. The Home Care nurse does the assessment for both the palliative care and convalescent care.

Advertising of services

The Home Care and Support Program is two years old, and there is good coordination between both hospital and Home Care and Support. Health and social supports are integrated into one division; this makes it much easier for clients to access and allows for easier planning and coordination of services.

Quebec

Services

People with AIDS are integrated into existing programs, so there is no need for a special Home Care Co-ordinator for AIDS, nor for special Home Care facilities.

There has been some fear of caring for people with AIDS, and they have usually been admitted to hospital. They would, however, be eligible to receive any special assistance, like Meals on Wheels, in the same way as anyone else.

Doctors:

A doctor's services are not provided through the Home Care program and patients usually go to a private practitioner. Urgence Santé will make home visits as part of the general health care.

The following services are included:

- Nurses
- Social workers
- Home makers and personal support services
- Personal care workers

Physiotherapists and occupational therapists are not included; these services are not well developed in the Quebec program, even for the elderly.

Clergy are involved, but more extensively with nursing homes.

Child Care would probably come under the Social Services; it is not a usual feature of the Home Care program.

Equipment

Medical equipment, including beds, can be provided.

Costs

Home care is free of charge.

Family and Respite Care

Family members can be paid for providing home care services, and drugs can be provided free if the individual has a low income.

Respite care is available: the patient would go into a special nursing home for a while.

Advertising of services

Home Care is usually associated with the needs of the elderly, so young people do not always realize that these services are accessible to them. In the future it is expected that it will be better known that anyone can apply, and that it is not restricted to any group within the community.

Saskatchewan

Services

People with AIDS have been integrated into existing services.

The southern part of the province is divided into 45 geographical areas or districts. Responsibility for provision of home care services in each district rests with a district home care corporation which is incorporated under the Non-Profit Corporations Act. The home care districts are responsible for planning, administering and delivering home care services in accordance with the Saskatchewan Home Care Act and Saskatchewan Home Care policies.

Purpose of the Saskatchewan Home Care Program

The purpose of the home care program is to preserve and maximize an individual's ability to remain independent at home by offering services that provide needed care and support. In achieving that end the program is intended to foster the widest possible use of available individual, family and community resources.

Doctors:

Patients do not have to be referred by a physician unless their condition requires medical orders, in which case they go through their own practitioner.

The following services are included:

Nurses

Home Makers and support services
Physiotherapists (some urban home care districts)
Occupational therapists (some urban home care districts)

All home care services are provided on the basis of an assessed need.

Every home care district provides the following primary services:

1. The assessment and care coordination service includes assessment and coordination of care for a specific client and the coordination of home care services with other agencies in the community.
2. The nursing service includes the provision of direct nursing care as well as the teaching of self care to clients.
3. The homemaking service includes personal care (assistance with activities of daily living, such as bathing, grooming, dressing, feeding, etc.), care of the bed bound client, exercises, routine foot and nail care and supervision of activities of daily living.

   Homemaking also includes general household cleaning, menu planning, meal preparation, laundry, ironing, mending, changing linen and other tasks.
4. The home care meal service includes meals on wheels, in which meals are delivered to clients at home and/or wheels to meals, in which meals are prepared and provided to clients at a central location.
5. The home maintenance services that are essential for the safety of the client.

Certain urban home care districts continue to provide occupational and physical therapy.

Community Physical Therapy Services are also available through the Community Health Services Branch of the Department of Health.

Social workers are only included on a referral basis.

Child care comes under the umbrella of Social Services.

Medical Equipment

All requisite equipment is available through the program, including oxygen and beds if necessary.

Eligibility for Home Care Services

Any one can make a referral to home care. However, the Saskatchewan Home Care Program requires applicants to meet one of the following eligibility criteria in order to have their application for home care considered:

a) hold a valid Saskatchewan Health Services Card; or

b) be in the process of establishing permanent residence in Saskatchewan and have applied for a Saskatchewan Health Services Card; or

c) be a resident of Manitoba or Alberta in a border area where contractual arrangements have been approved by Continuing Care.

Assessment

Before providing service, the home care district must assess applicants for home care using standardized forms provided by the Department of Health.

All decisions for care are made by the District Assessment Committee comprised of the senior staff of the home care district.

Costs of Home Care Services

Individual charges are based on the client's income and the number of services delivered to the client. Clients have the opportunity to apply for a subsidy:

- there are no charges for nursing services
- charges for meals, homemaking, and home maintenance service are based on income and the number of units of service received in a month. A unit is one meal or one hour of service
- everyone, regardless of income, pays $5.00 per unit for the first ten units of service received
- if a client receives more than ten units, the charge for each additional unit will depend upon the client's income
- no client will pay more than $300.00 per month. Clients receiving a full subsidy will pay no more than $50.00 per month

The Family, and Respite care

Family members cannot be paid for providing home care.

Counselling can be provided for the patient or family, but only through referrals; it is not part of the Home Care program.

Respite services are available through hospitals, special care homes and home care programs.

Advertising of services

Each District takes charge of its own advertising and public relations needs.

Home Care Services for Clients with AIDS

Individuals suffering from AIDS are assessed like all other home care clients, and services are provided based on assessed need.

Home Care districts have received special education to prepare them to care for clients with AIDS.

Yukon

Services

An interim Home Care program started in the Yukon in 1986. A more comprehensive program has been implemented earlier this year.

Doctors:

There is no provision for a doctor's services under the program, but patients continue under the care of their own practitioner.

The following services are included:

Nurses
Social worker
Occupational therapist
Home Makers and personal support services

There are three registered nurses on a part-time contract for Whitehorse, and in the Communities the Federal Public Health nurses work as needed.

There is one social worker co-ordinator in Whitehorse, who will do counselling and case management. In the communities there are Regional social workers who will work with the Home Care program.

There is no physiotherapist involved. There is a very great turnover of physiotherapists and occupational therapists, and people tend to stay in the Yukon a very short period of time on average.

There is one part-time occupational therapist for the program, who would have some responsibilities in visiting communities.

A number of Homemakers (some part-time) do personal care and housekeeping.

Information is being sent to the clergy, and it is hoped to interest at least some in becoming actively involved, besides their commitment to their sick parishioners.

A number of disabled children are cared for at home, but if there is a question of social problems it comes under the responsibility of Social Services.

The Home Care program will also be closely associated in working with the Hospice Society.

Medical Equipment

Equipment is provided through the Chronic Diseases and Disability program, but patients must be registered as chronically ill to receive this service. Recently the Human Rights Commission introduced the idea of AIDS as a disability. It should be noted that the Legislative Assembly of Yukon recently reviewed its position on sexual orientation as a prohibited ground of discrimination. Yukon is unique in having included protection against stereotyping through an "Assumed Association" clause in its Human Rights legislation. No other jurisdiction yet has this.

Some equipment is also provided by a separate program for Seniors.

Oxygen would be provided, and beds are lent periodically. Home Care itself does not have more than the minimal of equipment.

Costs

There is no cost to patients. Funding is provided through the government.

The Family, and Respite Care

Family members could not be paid for providing home care; if they needed extra help, trained workers would be supplied.

There is respite care to let the family care giver out of the home for a few hours a week. Alternatively, the patient can be placed in a hospital or Senior's Lodge for a while, but these arrangements are not always easy to make, institutions tend to be very busy, and it is not always straightforward to meet the needs of the people involved.

Advertisement of services

The Home Care program is currently being advertised. There has been an article in the paper, a talk on the radio, and pamphlets are being developed for distribution.

Summary

Special AIDS Teams

British Columbia, Ontario.

Evolving

Newfoundland, Northwest Territories.

Housing a Special Interest

Manitoba.

Strong Autonomy

Alberta, Nova Scotia, Ontario, Saskatchewan.

Extra Mural

New Brunswick (British Columbia reviewing).

Family Can be Paid for Providing Home Care

Northwest Territories (rare), Nova Scotia (In-Home Support plan), Prince Edward Island, Quebec.

Day Care

British Columbia (VON investigating in Nova Scotia).

Hospice

Federal

"The San Francisco experience shows that it is more compassionate and less costly to care for AIDS patients as much as possible in the community, [as opposed to a hospital] i.e., at home or in extended-care facilities. Where home care programs, hospices, or other appropriate alternatives to hospital care are advisable, provincial health ministries should provide and finance these alternatives."

AIDS: A Perspective for Canadians. Summary Report and Recommendations, Royal Society of Canada, April 27, 1988 ("Care of those infected with HIV," p. 6).

The Nova Scotia Task Force noted that it is often difficult to use American medical care models in Canada because in the United States Medicare is principally provided on a fee-for-service basis.

Alberta

Facilities

There is one residence for people with HIV infection in Edmonton. This is Karos House, which opened in the Fall of 1987 and has 10 beds. There has only been a small number of people staying there since it opened. Most persons with AIDS live at home if they are able to.

New Facilities

In Calgary the Grace Hospital has announced its intention to open a hospice in September 1989, which will admit patients with all diseases, including AIDS.

British Columbia

Facilities: hospices and hospitals

There are two funded hospice programs in B.C., and some hospitals have palliative care wards which function as hospices. Vancouver General Hospital is looking at the possibility of expanding from twelve to twenty-four beds. (This would be a general facility, not essentially for AIDS patients.)

Some long-term care facilities would probably prefer not to deal with AIDS. This often seems to be because of the administration rather than objections from the patients. When they have been requested to admit PWAs, the response has often been that they are full, and as they are independent, there is no means of pressing the issue.

Facilities: community hospice

There is a "community hospice" for terminally ill people including those with AIDS, similar in concept to the extra mural hospital system of New Brunswick. There are two nurse consultants, a social work consultant, a specialized physician and a core of volunteers based on a philosophy of care.

Facilities: group home

There is a group home for persons with AIDS or who are HIV sero-positive who have no (or very low) incomes. AIDS Vancouver operates McLaren House, which is run like Shanti House in San Francisco, but there is a shortage of funds to maintain it. Up to five PWAs can be accommodated at one time.

New facilities

It was strongly felt that there should be a number of options open to persons with AIDS, such as in/out privileges.

One of the "gaps" in on-going care is a shortage of suitable housing, although the establishment of McLaren House by AIDS Vancouver has done much to relieve the situation, and the City Council and Mayor are pressing for extra housing and hospice facilities. The Mayor's Task Force has recently tabled its recommendations (April 28, 1988).

The episodic nature of the disease creates peculiar difficulties for persons with AIDS. They are constantly in and out of hospital, but need specialized care in between bouts of infection. Very few PWAs die at home. Care is very rigorous for each episode of infection, and most patients are in acute care at the time of death. Hospice facilities can often maintain a valued balance between home surroundings and hospital care.

Any dementia is very difficult to manage in the community, and it is a common complication with AIDS, requiring acute care.

Manitoba

There is no hospice yet, but long-term care is being discussed.

New Brunswick

Facilities

There is one Hospice Program available in the province (Saint John). The program was designed to provide palliative care to clients requiring the services but was not developed specifically as an AIDS hospice.

There are two hospices, one in Saint John and the other in St. Stephen. Both are free-standing, near hospitals, and include the services of physicians, nurses, chaplains and volunteers. The one in Saint John has about 12 beds, and the one in St. Stephen is smaller.

The one in Saint John is preparing to get involved with caring for AIDS patients. Hospice staff are educating themselves towards this, and one of them serves with the Saint John Committee for AIDS.

Shortage

There is a waiting list for both of these hospices. There is a public demand for this kind of service because hospice care tends to take into account the needs of families in a way that hospitals can rarely undertake. There is often more flexibility over visiting hours, and more opportunity for the family to be personally included at the time of death.

It is intended to apply for government funding to increase the number of beds for AIDS patients. At this time the public in general must wait for beds on a first-come-first-served basis.

Community Groups

AIDS-related community groups are not yet actively involved with hospice care. This question is being brought up at the annual general meeting of AIDS New Brunswick.

The philosophy of hospice care can also be applied to the Home Care services.

Newfoundland

At this time there is no hospice in Newfoundland.

Northwest Territories

There is no hospice in the Northwest Territories in the sense of a free-standing building or hospital wing, but the term could be applied to the hospital respite care which is provided.

Nova Scotia

There is no hospice for AIDS in Nova Scotia.

Some hospitals in the province offer hospice programs for the terminally ill, including people with AIDS.

Ontario

Facilities

Casey House is a hospice for persons with AIDS who are terminally ill. It was set up as a component of St. Michael's hospital, and has access to round-the-clock nursing facilities. It is a free-standing building, but was funded through the hospital. It opened in Toronto on March 12, 1988.

Barrett House is a permanent home for those PWAs who have no home or place to go. It is operated by the Brothers of the Good Shepherd.

New facilities

There have been two or three enquiries about the possibility of setting up new hostels. These would only be seriously considered if they were justified by the local need, and also linked with community-based groups and the local Health Unit.

Prince Edward Island

Background

The Island Hospice Association was formed in 1986. There are three chapters, one in Queen's County and two in Prince. There is a Provincial Board of Directors. There is also an Executive Director and three Co-ordinators, one in Queen's County and two in Prince County. These three draw modest salaries, otherwise it is an entirely voluntary organization.

The Island Hospice Association is an educational body, and accepts speaking engagements to other organizations.

It was a national association, but this is no longer so, and no longer having a national image has resulted in their maintaining very little contact with other provincial or federal associations. This has been experienced as a loss in the realm of exchange of ideas and resource materials, which are beneficial in the training and upgrading of volunteers, especially in planning for a situation such as the care of AIDS patients.

The Island Hospice Association is not funded by anyone, and relies on its own efforts for its support. There is no fee to families whatsoever. During April, there is a Hospice Awareness Week, during which other organizations are contacted and visited. The Association works through community agencies such as social services, medical associations and through volunteers, the clergy and physicians.

Referrals

The majority of referrals come through Home Care and Support, and the two organizations work very closely together. Doctors on the whole have seemed reluctant to give referrals.

There is a Medical Director for the Hospice Care Unit.

Facilities

One hundred and fifty families have used the services of the Island Hospice Association in the two years of its existence.

There are eight hospice beds at the Doctor Eric Sound Centre. This is a long-term care facility. Some MS residents live there, and there is also a unit for convalescents. Services are subsidized, and covered by Medicare.

The Hospice Unit is set up in such a way that patients can go for a drive or go home for the weekend if their pain is adequately controlled. Patients may also come and go, or stay for the entire length of their illness, and they have choices as to how their care will be managed. However, the hospice prefers, if possible, to admit patients for at least three months, and feels that six months is much preferable.

Palliative Care and Hospice Care are viewed as being synonymous, that is, hospice care provides palliative care (as opposed to convalescent care). It is essentially a service to provide pain control, to maintain awareness and consciousness, and to increase the dignity of the individual at the time of death.

Staffing

There are no hospice nurses. The Unit uses either volunteers or tries to arrange for other community facilities, depending on the home situation. If an individual has Blue Cross coverage and needs individual care, they can hire a registered nurse for part of the day or night. Home Care nurses or workers can be called upon, and sometimes a family member is competent to take charge. The Hospice Association volunteers try to do home visits only during the day. The Meals-on-Wheels program is available for those who need it, and this is also run by volunteers.

If the patient is at home, private physicians make home visits quite readily, as the distance is never very far.

Family

The Hospice facilities are available to any Islander, but only in that one building and locality, and this can involve some travel for patients and their families who live at a distance. The possibility of providing designated beds in community hospitals is under discussion, but essentially Hospice Care is home-based, if the patient is willing and has someone at home who is capable of undertaking the responsibility. This can be difficult if a person lives alone, and some couples find that the husband can only cope for a while if it is the wife who is sick.

Hospice workers deal with the whole family, not just the patient. At the beginning of hospice care, the family is matched with a volunteer, who continues to support them until a year after the patient's death.

Equipment

The Red Cross is utilized for the provision of special equipment such as hospital beds, commodes or wheel chairs.

Oxygen can be provided through the Oxygen Equipment Centre, and the patient pays for that.

Policies for AIDS patients

There are only eight beds, and how many would be designated for AIDS patients depends on the numbers involved. About 99 per cent of patients at this time have cancer, and the number of persons with AIDS does not warrant special facilities for them. There has been some questioning about how well cancer patients would integrate with PWAs, partly because in general cancer patients tend to be older than the average AIDS patients, and have, perhaps, different needs.

PWAs would be absorbed into the existing services, and there is no policy to separate them. At present they are admitted to the hospital. It was felt that there might be fears among other patients, and it was uncertain how they might react. Since the Island Hospice Association has not developed policies to deal with AIDS yet, it was felt to be important to concentrate on AIDS education first.

Volunteer training

Volunteer training is offered twice a year, in Spring and Fall, to volunteers from both rural and urban areas. Training is being upgraded to integrate AIDS education, and includes a presentation of the Public Health film, "AIDS in the Community." There is a conscious effort to deal with small community fears and to broaden understanding of the disease and its management.

Quebec

Family placement

One or two persons with AIDS have been placed with designated families (similarly to the program developed for the handicapped).

Nursing homes

Some groups have expressed the need for nursing home care in between hospital visits. Such facilities might accommodate, perhaps, 10 to 12 PWAs for one to three months at a time, and would not be designed for the terminally ill so much as for a support for those who had nowhere else to go.

The Minister of Health has asked interested groups to write to her with their proposals. One will be financed in Montreal and one in Quebec City. So far a number of proposals have been received (one from a PWA group, one from a religious group, and one from a social worker in a hospital, among a mix of others).

Saskatchewan

At this time there is no hospice in Saskatchewan.

Yukon

A new Hospice Society is in the process of being developed to look after the terminally ill, and to provide support and counselling to the bereaved. (Bereavement services are already in place.)

Two people will be starting a volunteer training program in the Fall of 1988. Volunteers will be sent into both the hospital and private homes, and will be very closely associated with the Home Care program.

This model of hospice care does not involve the use of separate facilities or buildings, but is a society of volunteers dedicated to a concept of care.

Funding is being solicited from a variety of groups and from the government.

Summary

As with the term "palliative care", "hospice care" can be viewed as a philosophy of care, or applied to specific facilities which provide services based on such a philosophy. For this reason, sometimes the understanding of what is being said can be unclear or have an overlap of context. There is for this reason an ambiguity to the information about hospice care. Where provinces have said that they have no hospice care, it does not necessarily indicate that they have no philosophy for the care of the terminally ill, but simply that they have no physical and separate amenities for this.

Hospices can also be utilized for different services, such as a shelter for those that have nowhere to go, or as an intermediate home, as well as a care centre for the terminally ill, or a mixture of all these. The word Hospice can also refer to a system of community care such as a "hospital without walls," where there is no designated building, but hospice care is provided in the home. A hospice unit can also be a designated area within a hospital or nursing home. Other hospitals may not have a designated unit, but employ a philosophy of hospice care.

Hospice facilities were described, or a specific focus was emphasized, in the following ways:

Buildings or units designated as hospice and/or group homes: (10)
N.B. two; P.E.I. one; Ontario three; Alberta one; B.C. three.

Shelters and group homes for persons with AIDS
Ontario, Alberta, B.C.

No designated hospices
Newfoundland, Manitoba, Saskatchewan, NWT, Yukon, Nova Scotia.

Designated family placement
Quebec.

New hospices in planning stages
Alberta.

Palliative Care

Federal

"Canada is already recognized as a leader in the development of palliative care for patients with cancer. AIDS now challenges our society to extend its goals in this area of health care."

(Royal Society of Canada, AIDS: A Perspective for Canadians, Summary Report and Recommendations, p. 6, para 2.)

Alberta

Palliative care is provided as part of the Home Care program by the government-funded Health Units. Palliative Care services are also provided as specialties in several hospitals.

British Columbia

There is a palliative care philosophy in all treatment for terminally ill patients, whether it be in hospital or through home care. All home care nurses have training in palliative care.

A comprehensive manual, "Caring for the Person with AIDS", has been produced by the Vancouver Health Department with the assistance of the Provincial Ministry of Health's Continuing Care Division, to assist continuing care staff and long-term care assessors. It includes a detailed description of a variety of alternative drugs used for AIDS treatment in B.C., together with their dosages and side effects. It also has general statistical information, infection control procedures, charts for case assessment, nutritional management and recipes, and very detailed community resource information.

There is a companion handbook, on a much simpler level, for care givers, "Caring for People with HIV in the Community", by the City of Vancouver Health Department.

Manitoba

A Committee is working on all aspects of long-term care, but it has not completed its study yet.

New Brunswick

Modified palliative care services are available through the Extra Mural Hospital Program.

The Victorian Order of Nurses (VON) care for patients in the home.

Newfoundland

There is care of the terminally ill, but no specific palliative care service for AIDS patients.

Northwest Territories

There is no active program for palliative care in the Northwest Territories, although it is part of the acute care in any hospital treatment of terminally ill patients.

Nova Scotia

Palliative care may be provided in the hospital, in the home, or in a long-term care facility. At this time, most people with AIDS in Nova Scotia die in hospital.

Palliative care is given at the Victoria General Hospital (the major tertiary care hospital caring for AIDS patients in Nova Scotia) through a team of caregivers. This consists of three registered nurses and a group of trained volunteers. The nursing role consists of consultation, counselling, education, advocacy, clinical expertise, volunteer co-ordination, home support, and bereavement follow-up as required. One hospice nurse is assigned to a geographical area/service in the hospital and, therefore, one person consistently cares for all AIDS patients who are hospitalized.

In Nova Scotia, palliative care is available in several, although not all, areas of the province; but the need to deal with AIDS has been very limited because of the geographical situation of specialist facilities.

Ontario

There is no special palliative care program for persons with AIDS, but the existing services provided through hospitals, institutions and Home Care would be available to anyone of the general public.

Ontario Public Education Panel on AIDS (OPEPA) and the National AIDS Centre, Health and Welfare Canada (NAC), co-funded a 35-minute audio-visual "A Family Experience" about the impact of AIDS on one man, Don Robinson, and his family. It is designed for use with health professionals and with families of PWAs, and is available in Beta and VHS video formats in English.

Prince Edward Island

There is no palliative care service specifically for people with AIDS, but Home Care palliative care would be available, as it is for any of the general public.

Hospice policies have not yet been fully developed to include PWAs, but they are there in principle.

Quebec

There is a province-wide system of palliative care in Quebec, but not developed specifically for people with AIDS. It is available to patients both in the hospital and the home setting.

Saskatchewan

There are palliative care services at both University Hospital and St. Paul's Hospital in Saskatoon. The Saskatchewan Home Care programs also provide palliative care for individuals who prefer to be treated in a home setting.

Yukon

There is no facility for the extended care patient in Whitehorse. These persons are currently being cared for in the Hospital's medical ward.

Summary

In discussing facilities for palliative care, there was often confusion over the definition of meaning. Some people conceived of the term as a philosophy of care, and to others it suggested a physical facility, such as a building or ward. According to how the meaning is perceived, palliative care services can also be described as integral to those offered by Home Care, Hospice Care and Hospital Care.

Palliative Care services were described in the following ways:

Through hospitals, institutions and home care: (see separate section on home care)

N.B., P.E.I., Quebec, Ontario, Saskatchewan, Yukon, B.C., Alberta, N.S., NWT.

Through hospice: (see separate section on hospice care)

P.E.I. (in principle), Saskatchewan (may be developing a unit), B.C. (already well developed for PWAs)

For the terminally ill, with no specific policy:

Newfoundland, NWT

Studying all aspects of long term care:

Manitoba

Resources:

Audiovisual, "A Family Experience", co-funded by OPERA and NAC, Ontario.

Manual, "Caring for the Person with AIDS", by Vancouver Health Department with the assistance of the Provincial Ministry of Health's Continuing Care Division, B.C.

Handbook, "Caring for People with HIV in the Community" for Care givers, by City of Vancouver Health Department, B.C.

National

The Royal Society of Canada report, "AIDS, a Perspective for Canadians", released April 27, 1988, notes that social services need to be improved for both persons with AIDS and their dependent families. Quoting from page 7, it remarks:

"Persons known to be infected with HIV often face severe financial difficulties. They may lose their jobs or exhaust their sick leave benefits; they are likely to be young and may not have large savings. Inadequate financial resources and discrimination may lead to the loss of housing and other social problems.

Ultimately, as a compassionate society, Canada must take steps to sustain families impoverished by the illness or death of a wage earner".

The report goes on to recommend three steps:

Box 6, p. 7 - "We recommend that social benefits be improved to provide adequate financial support for people with AIDS and their dependent families. We further recommend that subsidized housing be made available to those HIV-infected persons who have social or housing problems resulting from their infection".

Box 7, p. 7 - "We recommend that compensation be provided to persons infected with HIV through the transfusion of blood or blood products".

Box 8, p. 7 - "We recommend cost-analysis and cost-effectiveness studies of selected projects of community support for HIV-infected persons".

Alberta

In Alberta anyone infected with the AIDS virus would go through the same Social Service system as anyone else.

There are guidelines for Social Services, and policies regarding AIDS are being implemented in various divisions of the Department of Social Services.

British Columbia

There are no specific guidelines for the Social Services for AIDS, and no special policies. Any person with AIDS needing assistance would go through the same channels as any other of the general public, and this is determined by need, not sickness.

Although there is no official policy, Financial Assistance Workers may exercise their own discretion to some degree, and if an individual is in great financial distress the process of assistance can be speeded up. Each case would be decided on its own merits.

AIDS has been defined as an illness, not as a disability.

Manitoba

There are no specific guidelines for AIDS for the Social Services, and no new policies.

Any person with AIDS who needed assistance would have to apply through the usual channels, and would be treated the same as any of the general public.

AIDS is defined as a physical handicap.

New Brunswick

There are no specific guidelines for AIDS for Social Services.

Social Service personnel, like other helping professionals, are beginning to implement AIDS-related staff education programs.

AIDS-related roles/responsibilities and implementation strategies are presently in the process of being further defined and developed for Community Health Division which includes Public Health, Mental Health and Social Services.

If there was a personal emergency, such as the sudden loss of a job or housing, the AIDS New Brunswick Program Co-ordinator would intervene as an advocate, and would try to make a referral to the appropriate agency or support service.

Newfoundland

There are no specific guidelines for the social services in dealing with AIDS, anyone infected with the virus would be treated through the same channels as anyone else.

There is no legislation to define AIDS as a physical handicap.

If a PWA needed urgent care of any kind and there was a delay in receiving the necessary services the government would see that they were provided.

Northwest Territories

There are no current policies for the Social Services for dealing with AIDS, but a pan-governmental policy is being considered through which individual departments would adapt what was relevant to their own services from the general overall policy.

Social Service workers have been included in AIDS educational sessions through the Department of Health.

Nova Scotia

There are no specific provincial guidelines for the provision of Social Services to PWAs as such cases are reviewable, as would be any other case. PWAs in need are by definition not excluded from the program. The disease does cause employment problems as employers cannot be assured (as neither can the PWA) that the employee will be able to come to work from day to day, due to health reasons. Once a person's health reaches the stage where they are sick on a continuing, yet intermittent, basis, then employability is severely reduced, and in some cases a PWA may be defined as disabled by physicians.

The Department of Community Services is reviewing AIDS education programs, with the intention of implementing AIDS education for staff in the near future.

Nova Scotia has two separate but inter-related types of financial assistance programs for persons in need:

1) a province-wide system known as Family Benefits, for certain categories of persons in need. These are the disabled; single parents; foster parents and senior citizens who are not eligible to receive Old Age Security payments. Family Benefits provides monthly payments where the cause of need is likely to last more than one year.

2) Municipal Social Assistance is provided by municipalities for persons who are likely to be in need only for a short period of time, or for persons who require long-term

assistance but do not fall within the categories eligible for Family Benefits. There are no categorical exclusions as with the Family Benefits program, and the primary eligibility crierion is the needs test.

The Family Benefits Act defines "disabled" as "having a major physical or mental impairment or a combination of physical or mental impairment that is likely to continue for at least twelve months, and which renders the person unemployable in the regular labour market ...." People with AIDS may not fall within this definition because of the episodic nature of the disease, and yet in fact be unemployable because of frequent bouts of illness.

Ontario

AIDS has been defined as a Disability, and so legally any person with AIDS has the rights to social services which the disabled or the chronically sick are entitled to.

The Ministry of Community and Social Services produced a booklet entitled "Understanding and Coping with Blood Borne Infections Including AIDS in Residential Facilities for the Developmentally Handicapped", which outlines protocols for these facilities.

People with AIDS are protected through the Human Rights Code, and discrimination based on sexual orientation is illegal. Almost all the social services are overburdened, and the policy of the government has been to integrate the needs of PWAs with existing structures. Because of the pressure of there not being very much time for those who are very sick, standard routines have been speeded up to enable those who are ill (including PWAs) to go on provincial income maintenance programs more quickly than usual if necessary.

Much of the help given PWAs is through community groups rather than through "official channels".

Psycho-social services have been identified as the most crucial for people who have tested HIV seropositive.

Prince Edward Island

Any person who was infected with the AIDS virus would have to use the same channels as the rest of the general public in applying for social services. There are no specific guidelines for the Social Services in dealing with AIDS.

Quebec

Social Services in the province of Quebec have created a special social work position to deal with people with AIDS or who are HIV seropositive. This has proved particularly important for Montreal.

There are also three counselling teams, two in Montreal and one in Quebec City.

Saskatchewan

Any person infected with the AIDS virus in Saskatchewan would access Social Assistance through the established social services system.

AIDS has not been given any special status for social assistance programs.

Yukon

There are no special guidelines or policies for the Social Services in dealing with AIDS. Any person who had AIDS or who was HIV seropositive would be treated in the same way as any other prospective client.

Summary

There has been very little produced for Social Services in the form of guidelines for AIDS, as the care of people with AIDS has largely been integrated into the existing services. Social Services are generally perceived as part of a team with other community support services such as Home Care agencies, community support groups, social work agencies, health care workers and clergy.

Specific observations included:

There are no specific guidelines for Social Services for AIDS.

Quebec, Ontario, NWT, B.C., Manitoba, N.B., Nfld., N.S., P.E.I., Yukon

AIDS is defined as a Physical Handicap

Manitoba

AIDS is defined as a Disability

Ontario, N.B., Manitoba

AIDS is defined as an Illness

B.C.

Social Services Counselling services created for AIDS

Quebec, Ontario

Social Service needs specifically handled through AIDS community groups

N.B., Ontario, B.C.

Book outlining social services available to PWAs

Ontario

AIDS is legally defined as a disability in federal human rights legislation, and provincially HIV + is classified as a "perceived disability".

Psychiatric Care

Medical Overview

"About one third of people with AIDS have significant difficulties due to neurological conditions associated with the illness ..... Impairments may be temporary or permanent, and may fluctuate in severity .... The most common course is gradually progressing dementia (AIDS-related encephalopathy) .... People with AIDS should be encouraged to arrange wills, powers of attorney, funeral plans and other practical matters early in the illness while they are mentally competent". (From: AIDS and HIV Infection, Psycho-Social Issues: Information for Professionals. Ministry of Health, Ontario, 1987).

Abstract of significant psychological stress detailed in Vancouver Department of Health nursing care assessment chart:

"Memory loss/confusion/threatened identity/loss of career/loss of financial stability/loss or rejection from family or friends/loss of control of destiny/loss of independence/loss of anonymity/altered body image/loss of physical or mental abilities/loss of spiritual support/grief/hopelessness/social isolation/stigma".

The dementia aspect of AIDS can be very disturbing to others. It is also sometimes the first symptom of the disease, and in itself can be diagnostic.

A palliative care study from the Department of Health by the Palliative Foundation of Canada indicates in its draft statement that the latest statistics suggest some form of mental deterioration, ranging from mild and stable to sever and rapidly changing, is present in approximately 60 percent or more of persons with AIDS. It also concluded that mental deterioration is a major problem during the terminal stages of illness, and creates specific care needs that may result in the need for special facilities.

(From: Caring Together, draft report of the Expert Group on Integrated Palliative Care for Persons with AIDS, Dec. 1987, p. 16 2.3/2.3.1)

Alberta

Psychiatric care for people with AIDS is integrated with general patient care in hospital.

There is a limited number of patients in mental hospitals. An internal discussion paper regarding the mental health care needs of HIV infected people is being prepared.

British Columbia

There are adequate psychiatric facilities through the present general services.

Dementia was mentioned as being very difficult to care for in the community, and need 24-hour care, especially so considering the blood and body fluids precautions which PWA's must take. Advocates for the need of a hospice advance this as one of their arguments, stressing that it is a common complication.

Manitoba

There are no special facilities for psychiatric care for people with AIDS at this point, but it would be considered later if the numbers warranted it.

New Brunswick

There is no separate model of psychiatric care for people with AIDS or who are HIV seropositive.

Psychiatric services in the province are provided through the Mental Health Clinic programs; the Hospital Psychiatric Unit program, and the two regional psychiatric hospitals. Persons with AIDS requiring psychiatric assessment and treatment would be referred to one of these programs.

Mental health counselling services are also provided by other mental health workers, i.e., nurses, social workers and psychologists, through the same programs.

Newfoundland

There are no special facilities for people with AIDS or who are HIV seropositive, they would use the same services that are available to any other patient.

Some patients with AIDS, however, might tend to be referred to a particular psychiatrist because of the fact that there are a few who have a special interest in the disease.

Northwest Territories

Seriously ill people are sent South, and for this reason patients with AIDS who are being treated in the NWT would only tend to be at a very early stage of the disease, or pre-diagnostic.

There has only been one case of AIDS so far.

Service patterns vary regionally.

Nova Scotia

There are no separate psychiatric facilities for people with AIDS in Nova Scotia; they are integrated into existing services.

MACAIDS facilitates referrals to psychiatrists for people with AIDS who wish to seek psychiatric counselling as part of its counselling and support services. Psychiatrists are available in most counties of Nova Scotia.

Social workers may provide professional counselling, act as patient advocates and co-ordinators of care, and also arrange referrals to other health professionals.

The Victoria General Hospital in Halifax currently has a long waiting list of HIV+ persons requiring psychometric assessment.

Attention is being given to the need for additional clinical psychologists with special training in the psychometric assessment of HIV+ persons, and on-going education for them.

Ontario

There are no hospitals designated specifically for psychiatric care for AIDS in Ontario.

People with AIDS tend to be admitted to infectious disease units, and are integrated on to the general ward. If necessary, a patient would be treated for psychiatric care appropriately.

Each psychiatric hospital has had special training in the care of dementia related to AIDS, and been advised to take universal safety precautions.

The psychiatric Unit at Mt. Sinai Hospital has a special interest in AIDS.

Prince Edward Island

Psychiatric counselling is not part of a program for AIDS per se, but people who have been infected with the virus and who need special care would probably be sent to the Psychiatric Institution in PEI.

Quebec

Psychiatric care is a very difficult issue at this time. Patients with neuro-AIDS need special care, and there is no ward or special program for these patients. Whatever possible has been done under the present facilities, but the issue is becoming a serious problem.

Saskatchewan

AIDS patients may be treated in existing psychiatric facilities, if such care is indicated.

Yukon

There has only been one case of AIDS. Patients who become acutely ill and who need facilities that are not available in the Yukon are evacuated to Edmonton or Vancouver.

There is a local psychiatrist and a very active mental health program which would accommodate people with AIDS.

Summary

When psychiatric care was discussed, no province or territory mentioned separate facilities for AIDS patients.

There are no special (separate) facilities for psychiatric care for people with AIDS.

New Brunswick, Newfoundland, PEI, Quebec, Ontario, Alberta, Manitoba, Saskatchewan, Yukon, NWT, British Columbia, Nova Scotia

People with AIDS would use the same psychiatric services as any other of the general public.

New Brunswick, Newfoundland, PEI, Quebec, Ontario, Alberta, Manitoba, Saskatchewan, Yukon, NWT, British Columbia, Nova Scotia

Dental Facilities

Federal

Universal safety guidelines for dental care have been strongly recommended by the Canadian Dental Association for the treatment of all patients, whether or not they have been infected with the AIDS virus.

These recommendations were developed and published by the Centres for Disease Control, Atlanta, Georgia, in the Morbidity and Mortality Weekly Report 1987; 36 (suppl. no. 25); 35-185. The Federal Centre for AIDS, in collaboration with the Bureau of Communicable Disease Epidemiology, Laboratory Centre for Disease Control, endorses these recommendations.

Safety procedures include the wearing of gloves, surgical masks, protective eye wear or chin-length plastic face shields for any procedures which might involve splattering of blood or body fluids, as well as the sterilization of all implements, equipment and intra-oral devices.

Alberta

Private dentists have been encouraged to treat people with AIDS. In Calgary, one dentist provides care to many AIDS and HIV sero-positive patients. There have been some problems with dentists accepting patients with this disease for on-going care.

Another dentist in Calgary operates out of a hospital.

In Edmonton, the University of Alberta Clinic treats people with AIDS.

People who have AIDS often have severe oral infections and tend to gravitate towards the more experienced dentists.

British Columbia

There is a dental clinic at Vancouver General Hospital for people with AIDS. It is also for high-risk infections, like hepatitis and immuno-suppressed diseases.

There is a new direction towards taking universal precautions. Dentists are changing their behaviour, wearing gloves and sterilizing drills and implements. The College of Dentists is also recommending disposable needles and puncture-proof containers.

Manitoba

There are no designated dental facilities for people with AIDS or who are HIV sero-positive, but the Dental College and some dentists provide dental care.

The Ministry of Health produced "Interim Guidelines for Dentistry" in July 1987, dealing with Workplace Prevention and Management of AIDS and HIV+ in which dental health care workers who have open lesions or active dermatitis are advised to refrain from all direct patient care and from handling patient care equipment until the condition is resolved.

Current recommendations state that dentists should use appropriate precautions at all times, and so it is not considered necessary to have designated facilities to deal with HIV positive clients.

New Brunswick

There are no dental clinics or facilities specifically for persons with AIDS or HIV infection. Dental care is provided through family dentists.

Newfoundland

There are no dental clinics or facilities specifically for persons with AIDS or who are HIV sero-positive in Newfoundland.

Northwest Territories

There are no special facilities for AIDS or HIV sero-positive dental patients, but there has only been one case to date.

Nova Scotia

The Nova Scotia Dental Association has taken the position that all dentists can and should treat HIV+ persons in their offices unless they are in advanced stages and have other medical complications, in which case the delivery of dental care in a specialized institutional facility would be necessary.

Dalhousie Dental School, in conjunction with the Nova Scotia Dental Association, established a special clinic for hepatitis and AIDS-related disease in the fall of 1987. One room is set aside for this purpose, where blood and body fluids infection control procedures are observed.

At present there are only two hospitals in the province which provide comprehensive dental services to HIV infected persons. The Izaak Walton Killam Hospital provides dental care to children, and the Halifax Infirmary to adults. The Victoria General Hospital provides only surgical dental services to HIV infected adults.

The Department of Health distributed guidelines for personnel practising dental care in January 1985 ("Guidelines for Handling Patients With Suspected or Confirmed Acquired Immunodeficiency Syndrome, AIDS"). As well, the Canadian Dental Association distributed to all dentists "Recommendations for Infection Control Procedures" and the CDA "Statement on the Ethical and Legal Considerations of Treating Patients with Infectious Diseases." The Nova Scotia Dental Association also sent out to all its members the American Dental Association "Infection Control Recommendations for the Dental Office and the Dental Laboratory."

Dentists have been recommended to comply with blood and body fluids precautions. These include the wearing of gloves, mask and protective eyewear as a routine practice. These are not being followed in all dental offices. These infection control precautions can be time consuming, costly, and perhaps alarming to the patient, at least initially.

Ontario

There are no specially designated dental clinics or facilities for persons with AIDS in Ontario. The government policy is to integrate AIDS care as much as possible with existing services.

Dental services for AIDS patients tend to be very discretely handled because of public anxiety over the fear of transmission of the disease.

No dentist may legally turn away a person who is infected with the AIDS virus on these grounds alone, but there has been some reluctance among dentists in general to handle the care of persons who are known to have the disease.

Prince Edward Island

There are no special dental clinics or facilities for AIDS, but the Dental Association has discussed the possibility of providing them if the need should arise.

Quebec

There is one dental office catering to people who are infected with the AIDS virus in Quebec.

There is only one dental surgeon offering his services, and he has only just very recently begun to do this. He practises within the hospital dental clinic.

He has not received special financing for this.

Saskatchewan

A number of dentists are willing to treat persons who are HIV/antibody positive.

Yukon

There are no special facilities for AIDS dental patients in the Yukon, but there has only been one case.

Summary

The Dental Association has strongly recommended that dentists should employ infection control procedures for all patients. Because there are so many private dental practitioners, it is difficult to estimate to what extent infection control procedures are being followed without undertaking a specific study of this. The information given was necessarily a personal impression of general local trends.

One of the difficulties facing dentists is the fearful attitude of the general public, the intimate nature of the treatment, and the anxiety for themselves of risking losing a significant number of clients if they treat persons with AIDS.

The following observations were made:

There are designated dental facilities for persons with AIDS:

Quebec (one dental surgeon in a hospital clinic)
Alberta (one private dentist, one dentist in a hospital clinic, one university clinic)
Saskatchewan (one dental clinic)
B.C. (one dental clinic)
N.S. (one dental clinic, three hospitals)

There are "unofficial" dental facilities for persons with AIDS

Ontario (one hospital clinic)
Manitoba (the Dental College and some gay dentists)

National

In March, 1988, the Federal/Provincial/Territorial Advisory Committee on AIDS agreed in principle that the report by M.A. Somerville and N. Gilmore "Human Immunodeficiency Virus and Antibody Testing in Canada" (McGill Centre for Ethics and Law, Jan. 6, 1988) "should be used as a framework document" by the Committee in examining the HIV antibody testing issue.

The recommendations of this report were approved by the National Advisory Committee on the Acquired Immunodeficiency Syndrome (NAC-AIDS) Dec. 9th, 1987.

This document by M.A. Somerville and N. Gilmore presents a "hierarchy of recommendations", or six classifications related to HIV testing, (page 46, Section II)

1) Unwarranted (i.e., unjustifiable)
2) Not necessary
3) May be advisable
4) Recommended
5) Strongly recommended
6) Essential

It also recommends three modalities for antibody testing, (Section II, page 47)

1) **Voluntary** testing, where testing is done only with the informed consent of the person to be tested (or if the person is incompetent, of his or her parent, legal guardian, or next-of-kin, as required by law), and the testing does not fall within the definitions of mandatory or compulsory testing;
2) **Mandatory** testing, where testing is either a necessary prerequisite for a person to obtain a specified status, benefit, service or access to a given situation, or is a necessary consequence of being provided with one or more of these.
3) **Compulsory** testing, where testing is required by law, or policy, and the person has no choice to refuse testing and cannot legally avoid it. This may also be termed involuntary testing.

Groups or individuals were identified under these classifications specifically in Section V, p. 50-100

1) **Unwarranted** (unjustifiable): For persons seeking insurance (except when mandatory testing is done to avoid potential harms or to minimize real harms). For persons entering Canada, (but they should be informed about HIV infection, safe behaviour and that voluntary HIV antibody testing is available). This applies to those who would be eligible for Canadian health care benefits as well as those who are ineligible.
2) **Not necessary**: For premarital, preconceptual and prenatal groups except where there has been participation in high risk behaviour; for men and women who are engaging exclusively in heterosexual activity, in the absence of other risk producing behaviour; for health care personnel on the grounds of transmission to patients; for persons seeking or receiving health care; for

children entering or in school; for children entering or in day-care centres; for children being assessed for placement or in foster homes; for employees and persons seeking employment; for persons in or seeking entry to military service; for children being evaluated for adoption.

3) **May be advisable**: for persons who, since 1978, have receive unscreened blood transfusions; for health care personnel who have been accidentally occupationally exposed to HIV; for persons in non-correctional or correctional facilities.
4) **Recommended**: For persons who, since 1978, have received tissue or organ transplants from unscreened donors; for women who, since 1978, have been artificially inseminated with semen (sperm) from an unscreened donor; for residents of areas where HIV infection is endemic; for men engaging in risk-producing homo-sexual activity; for persons working in the sex industry; for persons being evaluated for sexually transmitted diseases.
5) **Strongly recommended**: for persons who, since 1978, have received unscreened blood products; for persons sharing injection equipment during drug abuse; for health care personnel who have had documented accidental occupational exposure to HIV; for persons seeking or receiving health care who are the source of accidental occupational exposure of health care workers.
6) **Essential**: for all blood, organ, tissue, ovum or sperm donors.

The general findings of the report were that mandatory HIV antibody testing is essential for all blood, organ, tissue, ovum and sperm donors, but at this time, in Canada, compulsory HIV antibody testing is unwarranted. (Section V, pages 51 and 49, and Executive summary pages 10-21).

The report also discussed in some depth the ethical, social, legal and economic implications of HIV antibody testing, surveillance and contact tracing. (Executive summary pages 1-15 and Section I pages 23-44).

Ethical

Each of the recommendations in the report are based on strongy defined principles of respect for persons; non-maleficence; beneficence and justice. (Introduction, page 2). "Before deciding who, or when someone or a population, should be tested for antibodies, the ethical implications of such testing must be fully examined" (Section I, page 33), ... (and) "justification of any decision to test is an obligation of those who propose or would implement testing". (Section I, page 34).

Social

Social implications are an extension of ethical decision. "As a general principle, the potential benefits, and benefits for persons being tested, must outweigh the potential harms and harms for them . . . . potential harms . . . . may include psycho-social stress, disadvantage or wrongful discrimination". In the case of the community, these may include "discrimination, disadvantage, stigmatization or isolation of the community to which the HIV infected persons belongs; and increase in risk-producing activity; the costs of testing; or the costs of its consequences. Where testing is justified, provision must be made to minimize and compensate for the negative consequences that may result from HIV antibody testing, which may include: loss of privacy, shelter, employment, or insurance; wrongful discrimination; and other injury or distress". (Section I, pages 34-35).

Legal

Legal implications of HIV antibody testing are discussed in Section I.pages 35-38, and are also an extension of ethical issues. "Informed consent, obligations of confidentiality, rights or autonomy and privacy, and definition of mental incompetence are all legal concepts,as well as being important in ethical analysis". (pages 36-37)

The report discusses the general law and its applications to AIDS, including the new Canadian Charter of Rights and Freedoms, and the variation between provincial legislation, (page 37), but stresses that the "law should not in itself be the primary determinant of our approaches to HIV antibody testing (or, indeed, to the AIDS situation as a whole). Rather, both the enactment and application of law should reflect and institutionalize our ethical responses to the AIDS situation, whether that law is in the form of express legislation dealing with HIV infection and disease, or more generally applicable law . . . . great care is needed before adopting a legal approach as a potential solution . . . . We must also keep in mind that law both reflects and forms us and our society, including our values and the overall ethical tone of our society. The law that we could enact and apply in relation to HIV infection and disease will do no less, which means that it will have important effects far outside the AIDS situation". (pages 37-38)

It was also noted that it is "fortunate that Canada has not followed the lead of some other countries in being overly activist in enacting law to deal expressly with the AIDS situation, and that the only response of Canadian legislatures has been to include AIDS in provincial "Public Health Protection Acts" with other communicable diseases,and as a result, to deal with it similarly". (pages 37-38) In December 1985 the federal legislation section 253 of the Criminal Code (R.S.C. 1970 c. 34 as amended) which made it an offence to communicate certain sexually transmittable diseases was repealed. (Section I, page 38)

Economic

The report recommends that "no testing programme, whether voluntary, mandatory or compulsory, should ever be implemented until the monetary and human resources, necessary to implement it, are realistically available and readily accessible, especially those for counselling and education. Consequently, there are absolute obligations on the entire community, and especially its government, to ensure that appropriate monetary and human resources and facilities are allocated for this purpose".

It lists both direct and indirect costs of testing. Among the direct costs is the cost of testing itself, counselling, education, confidential record keeping, and psychological and social support services. Indirect or negative costs can include loss of employment, revenue, housing, education, insurance, business revenue, disability pension and compensation benefits. One of the most intangible and difficult areas to assess are psychological and demoralizing effects on individuals and Canadian society. "This is an area demanding major research efforts". (Section I page 33 and 29)

The report also examines the importance of counselling, contact tracing, confidentiality, erroneous results and the right "Not to Know".

Of **counselling**, it recommends: "At this time, in Canada, HIV antibody testing should only be performed when counselling and education are realistically available to help persons being tested to diminish potential psycho-social impact, and to enable and reinforce changes in behaviour which will prevent or minimize HIV transmission". (Section I, page 29).

Of **psycho-social stress**, the report warns of the grave harms that can result from testing. Depression and suicide may result from the stress of recognition that AIDS is at this time usually a terminal disease. Other stresses are that a person who is HIV sero-positive may have to "postpone conception, modify sexual relationships or behaviour, or the loss of friends, employment, housing, educational or travel opportunities". (Section I, page 29)

Of **informed consent**, the report says, "... the doctrine of informed consent requires that limitations of knowledge about HIV infection and its consequences, and about technology relating to the detection of HIV infection must be clearly identified, defined and communicated to persons being tested, before their consent to be tested will be legally valid". (Section I, pages 31-32).

Of **contact tracing**, the report recognizes that is can represent a professional, legal or ethical dilemma for physicians (section I page 40), and that they can have conflicting obligations to protect confidentiality of persons being tested and to warn others that they have been exposed to HIV infection, or have exposed or are exposing others. The report quotes the recommendations of the National Advisory Committee on AIDS statement on contact tracing (Canadian Diseases Weekly Report 1987: 13: 13-14) and the prelude that contact tracing adopt a "least invasive" approach, and strongly endorses these guidelines (Section I, pages 42-44).

It also emphasizes that "contact tracing by a third party without the express consent of the person being tested is an invasion of the person's right of privacy and a breach of confidentiality, and places that person at risk for disadvantage or discrimination. Consequently, such contact tracing must be justified. . . .".

It was pointed out that mandatory contact tracing risks the loss of co-operation of the person being tested, and that this co-operation is essential for effective contact tracing. (Section I, page 41)

Of **confidentiality**, the report remarks, "It is especially important to appreciate the vulnerability of anyone being tested . . . . consequently confidentiality must be assured, or testing must be done in an anonymous (non-nominal) way that fully protects the person being tested.

Of **erroneous results** the report says that "false negative" and "false positive" results represent a small proportion of all testing results, but the implications can be "serious and far-reaching". (Section I, page 31-32). "The proportion of all seropositive persons who are falsely positive will vary with the prevalence of infection in the population being tested. . . . Any decision to implement a large-scale HIV antibody testing (screening) programme must acknowledge the false positive results that can occur with the use of tests that are currently available. It must justify the potential harms, . . . minimize the harms that result . . . . and compensate for them when they are unavoidable". . . . Knowledge remains incomplete and technology often remains inadequate to provide specific or unequivocal information about HIV infection and its consequences. Any use of HIV antibody testing must clearly recognize this uncertainty". . . . (Section I, page 31).

Of the "**demand not to know**" the report points out that "such refusals of information are ethically controversial and sometimes could be legally unacceptable" . . . and . . . "in this situation, persons who are not informed of their testing results must be instructed that they have an obligation to behave safely, acting as though their test results are positive . . . In addition, it does not obviate the obligation of contact tracing." (Section I, page 32)

Surveillance, Research and Anonymous Testing

The report recognizes that "the collection of HIV antibody testing data for purposes of surveillance or research is a legitimate and necessary activity. Today, there is urgent need for these data". It quotes from the National Advisory Committee on AIDS recommendations (October 19th, 1987) 3.2, which suggests the ethical conditions under which seroprevalence studies may be carried out. (Section I, page 39)

The collection of data may be done: "prospectively or retrospectively; with or without personal identification of the person being tested, or of specimens or data (i.e. nominal, non-nominal or anonymous testing); or with results that are linked or unlinked to the person as source of the specimen. Where personal identifiers are used, or where results can be linked to an individual, then all persons being tested:

1) Must be fully informed of the potential benefits, potential harms and harms of such testing;
2) Must consent to being tested;
3) Must have access to their own results, and to care, counselling and interventions that their results may require;
4) Must be given a guarantee of confidentiality of results.

"Anonymous, non-nominal or unlinked testing are the preferable options by which to obtain HIV antibody surveillance data". However, although this offers the individual the greatest protection, it does not necessarily protect the population, community, organization or institution to which the persons who have been tested belong, if there is disclosure of the data. The consequence of such disclosure might be loss of reputation, revenue, or freedom of action, and "therefore any decision to implement such testing must consider the potential harm and harm that may result to others, including the population, community, organization, or institution where samples are obtained". (Section I, pages 38-39)

Federal Committee on AIDS Meeting

Of more specific information about individual provinces, the Federal Committee on AIDS held a meeting on surveillance in September 1987 in which it was agreed that the FCA should carry out a validation study using death certificate data from Stats Canada.

Two systems of surveillance are in use, passive and active. The passive surveillance relies on physicians to initiate a report. Active surveillance has begun in some provinces. Manitoba, Newfoundland and Ontario analyze death certificate data. In BC death certificates and hospital statistics are reviewed by the Medical Officer of Health, and HIV seropositive results are followed up to determine cases of AIDS.

It was suggested that reporting physicians should be contacted by the Public Health System within each province every six months to update the death statistics on AIDS patients and find new unreported cases. Deaths may be reported by month and year only, and identifying the cause of death (Pneumocystis Carinii Pneumonia or Kaposis Sarcoma) "could be fruitful".

The Federal need for patient indentifiers only requires initials and the date of birth. This is done to prevent duplicate reporting and facilitiate communication between federal and provincial programmes with regard to specific cases. The provinces may have a variety of patient identifiers.

Alberta

Reporting

AIDS is reportable
HIV+ is reportable, but not by name.

There is a non-nominal system of reporting. The specimen is sent to the laboratory with only a number, and reported to the patient's doctor. Aggregate data are reported to the Director of Communicable Disease Control.

Laboratory

There are two Provincial Laboratories of Public Health and one private lab doing HIV antibody tests. The Provincial Labs have received increased funding and have employed extra staff to cope with the massive increase in HIV-related tests (approximately 12,000 per year).

Tests

Two ELISA tests are done, followed by a confirmatory WESTERN BLOT test.

Counselling

Tests are carried out in a number of ways:

- Through a private physician
- Through STD Control (which has employed extra staff)
- Through Infection Disease specialists

The Province provides pamphlets on counselling to all doctors. There is no control over the way it is done in fact.

If it is chosen to go a STD Clinic or an Infection Disease specialist, there is guaranteed intensive counselling, both before and after testing. Results are not given out over the phone. People who are seropositive are also given sources of support and assistance, and pamphlets are given to both HIV + and HIV- clients.

In the case of going through a private physician, because the Provincial labs do most of the testing, the results are made available only to the doctor. This helps to ensure counselling regardless of the results, as the patients obtain their test results from their own physicians.

There are no regulations about ordering tests or counselling.

Alberta Health Care is usually billed for drawing of the blood, although patients can pay their own fee to protect confidentiality. The tests are done without charge, as the Provincial Laboratories are funded by government.

Contact Tracing

Contact tracing is done through STD Control if patients and their private doctors wish assistance.

Insurance Companies

At present there is no government control over testing required by insurance companies, and there have been no major problems with them.

Surveillance

HIV + is not reportable. Risk Factor Data is collected on persons who are tested. There have been 649 HIV seropositive results out of about 21,000 people tested (as of July 1988), but some may be duplicates. A seroprevalence study of women presenting to a STD clinic has been undertaken.

The province plans to maintain a surveillance mechanism of incidence and prevalence of HIV infection and AIDS, to evaluate the effectiveness of education and risk reduction activities.

Alberta has representation on the National Committee examining needs for seroprevalent surveys.

British Columbia

Reporting

AIDS is reportable

HIV+ is not reportable, although results are nevertheless reported by the laboratory to the Director of STD Control, but not by name.

Laboratory

There is one Provincial laboratory that does the testing. It was the first in Canada to provide testing to physicians and private clients on request.

A new Lab Level 3 contains the HIV isolation laboratory to culture the AIDS virus, and all antibody testing was moved into these facilities too. A million dollars was expended on these last year, and at least three or four new staff were added to take care of testing, which amounts to over 3000 tests a month. There have been 368 people with AIDS since 1983, 192 of whom are still living. (2200 people have tested HIV+, and there are an estimated 5000-6000 people who are HIV infected).

In addition to routine antibody screening during regular working hours, there is a twenty-four hour donor screening service and around-the-clock emergency screening for organ and tissue donations. A private laboratory in the States has also been approved to deal with immigration.

Tests

Tests used are the ELISA confirmed by the WESTERN BLOT method.

Counselling

All physicians in BC can order tests, and, since October 1985, any physician can initiate counselling. The results are sent back to the doctor. All doctors have been sent a handbook on how to do the testing and counselling, together with other information, and are kept regularly up-dated. It is recommended that counselling be given both before and after testing, but it is difficult to ensure. There has been a very successful training programme initiated by a general practitioner with STD Control, dubbed "The Travelling Road Show". He is sponsored by the BC College of Family Practitioners, and travels throughout the province giving talks and showing videos and printed materials. This will probably become a national programme as it has created so much interest. There is no other special training programme for GPs.

Twenty-two Health Units all do testing.

A Division of STD Control operates a daily clinic at the BC Centre for Disease Control in Vancouver.

There are training workshops for all Health Unit nurses and government Testing Clinics.

People who live in isolated areas are encouraged to use the Health Unit or go to Vancouver in order to protect their privacy.

Contact Tracing

There is a very simple system of contact tracing: the client is encouraged to locate any sexual contacts. If it is preferred, it can be done through Public Health, or by the physician in collaboration with STD Control.

Insurance Companies

There has been some difficulty with insurance companies in that there is suspected to be a private laboratory which has been established without permission or clearance. The Medical Devices offices in Ottawa have been advised, and they are investigating the matter.

Pamphlets

Two very detailed pamphlets have been produced about Antibody Testing:

"AIDS Antibody Testing: What It's All About," produced for people who are considering testing

and

"Information for Physicians of AIDS and Human Immunodeficiency Virus (HIV) Antibody Testing," which gives extensive information for doctors.

Surveillance

Between October 7, 1985 and December 31, 1987 42,488 samples were submitted for testing,out of which 1,921 were positive.

HIV+ is not required to be reported legally, but the Lab sends results to the Director of STD control. The Risk Factor information is required on the serology requisition form, and as of September 1987 this has not been completed on about 40% of requisitions. It was thought that there may be some duplication.

The majority of HIV-positive tests have been among male homosexuals and bisexuals. (Males 1,453, females 3, unspecified 4)

Manitoba

Reporting

AIDS is reportable by physicians – by name.

HIV + is reportable by laboratories – non-nominal (code).

AIDS cases are reported to Communicable Disease Control by the physician. HIV + is reported by the Public Health Laboratory. Voluntary testing is encouraged.

The only mandatory testing is for organ, tissue and body fluid i.e., blood and breast-milk donors.

Confidentiality issues are stringent.

[illegible]ratory

[illegible]e diagnostic testing is done in the one Provincial Laboratory. It has not been necessary to [illegible] or build new facilities, though space for AIDS testing has been provided within the lab. [illegible]t been a need to hire extra staff. Viral isolation technology will be associated with ex[illegible]ities and additional staff.

Tests

Screening tests: ELISA
Confirmatory test: IFA.

Counselling

Policy recommendations, developed in 1985, have been sent out to all physicians. They may provide their own counselling, or make referrals to other professionals who have received special counselling training courses.

Counselling is given both before and after testing.

Normally there is no fee for testing individuals, but there is a charge back to insurance companies for third party testing.

[illegible]t Tracing

Contact tracing is done through a nurse, and is voluntary.

Insurance Companies

The Great West Life Insurance Company sends tests to the USA. This is being discussed at the Federal/Provincial level, but no policies have been formed yet.

Surveillance

As of September 1987, there have been 100 HIV seropositive results reported since 1985 (primarily homosexual males). The Risk Factor and clinical information is requested on the Laboratory Requisition Form, and this is generally completed. The Patient Code number includes the last two letters of the mother's name and one other number. A seroprevalence study of High-Risk individuals entitled "Manitoba AIDS Virus Infection Study" was co-ordinated through the Cadham Provincial Laboratory.

New Brunswick

Reporting

AIDS is reportable

HIV + is reportable by name

Both AIDS and HIV seropositivity are legislated reportable conditions in New Brunswick. Reports are made through the family physician to the District Medical Health Officer. HIV reporting requirements are the same as legislation for other communicable diseases, which specifies that the name of the infected individuals should be provided to the District Medical Health Officer (D.M.H.O). However, physicians and D.M.H.O.s are being encouraged to consider non nominal reporting as the general rule in reporting HIV seropositivity and AIDS.

Laboratory

At this time (August 1988), specimens for HIV testing are sent to the Victoria General Hospital in Halifax, Nova Scotia. Several laboratories in New Brunswick have requested permission to perform the ELISA screening test.

Tests

The ELISA test is used, confirmed by the WESTERN BLOT method.

Counselling

The Department of Health recognizes and promotes the need for appropriate counselling prior to and after testing.

Any local physician may do both testing and counselling. There is no standard of counselling required of physicians in private practice, and this is being discussed.

A large proportion of people go through the Reproductive Health Clinics. Besides providing a recognized standard of counselling both before and after testing, regardless of the result, there is a referral system for those clients whose results are HIV seropositive. There is a Positive Support Group which has been started recently, which will keep in touch with the client and give on-going counselling. Nurses at the Reproductive Health Clinic also have maintained contact with patients on a long-term basis, and later included support for their parents and family.

AIDS New Brunswick has referred a number of clients to Bangor, Maine, where there is an anonymous testing service with excellent counselling facilities, and this Bangor service has been widely used.

Contact Tracing

The Department of Health takes the stand that contact tracing which is based on co-operation and a trustful relationship between the physician and the client can be an effective public health measure in assisting to prevent the spread of HIV infection. The Department encourages the client and physician to carry out appropriate contact (tracing) notification. The Department will also provide contact tracing services on referral from a physician.

Some doctors have expressed the need to clarify issues about the right to tell the spouse of a bisexual male that he is infected with the AIDS virus if there is reason to think she does not know.

Surveillance

Cases are reported to the Provincial Department of Health. Risk factor and demographic information is collected on a serology requisition form. The Identification number is a unique one which identifies the region and year.

As of April 1988, 77 individuals had been reported as being HIV +.

Newfoundland

Reporting

AIDS is reportable.

HIV + is reportable, but not by name.

Currently there is a non-nominal system of reporting, using only codes. The results are reported to the Provincial Health Department. Current provincial legislation does allow for nominal reporting.

Laboratory

There is only one laboratory doing testing, the Provincial Laboratory in St. John's. It has not been necessary to plan for new or larger facilities, but one person has been trained to deal with AIDS.

Tests

The Provincial Laboratory is only screening using the ELISA test. HIV seropositive specimens are sent to Halifax for confirmation, using the WESTERN BLOT method.

Counselling

Counselling can be done through any private physician or through the STD Clinic located in St. John's.

In the case of a physician ordering the test, the quality of counselling cannot be easily checked. Physicians were circulated information describing how the test works, how to order tests and how to counsel for AIDS. They do the pre-test counselling, and then if the result is positive the Provincial Public Health Office contacts the doctor and offers assistance with the post-test counselling or follow-up.

If testing is done through the STD Clinic, the client can be assured of getting appropriate counselling.

There is no fee for testing.

Contact Tracing

Contact tracing is done through the private physician with Public Health support, or through the STD Clinic.

Insurance Companies

Insurance companies are controlled by the Laboratory Act and there has been no difficulty related to AIDS in Newfoundland.

Surveillance

A registry of seropositive cases has been developed. The Risk Factor is obtained by the Provincial Health Department through telephoning the physician who ordered the test. Duplication is avoided by using the health care insurance number and the initials of the individual.

Northwest Territories

Reporting

AIDS is reportable
HIV + is reportable, but not by name.

There is a non-nominal system of reporting. Results are sent to the Regional Medical Officer.

Ethical views about testing are being reviewed, and testing is being promoted only for those who are in groups associated with high risk activities. Testing is thought to have very limited value as a control in an area where there is a low number of known cases, and to promote a false sense of security. Guidelines have been developed, taking these viewpoints into account.

In many Northern communities, the emergency blood supply from the South, which is already screened, is supplemented by local donations from individuals who are on an emergency donor list. In order to protect the emergency supplies, these donors are now being screened on a regular basis.

Laboratory

All specimens are sent away to Southern laboratories.

Tests

Tests used are the ELISA screening test confirmed by the WESTERN BLOT.

Counselling

All health care services are provided by the government, and private physicians use government hospital facilities.

In remote communities, testing is done in the nursing station in accordance with a comprehensive guideline. In order to ensure adequate pre-test counselling, and since testing is not considered to be an emergency, an appointment could be set for a few days later so nurses can avail themselves of a telephone back-up service. Great care is taken to ensure adequate counselling, both before and after testing.

Workshops are provided for physicians and nurse counsellors by the Department of Health.

Contact Tracing

Contact tracing within the community may be done by the nurse or doctor primarily involved. Out of community contacts are reported to the Medical Officer of Health for follow-up, but only after the patient has been informed that this is going to be done.

Insurance

There has been no problem with insurance companies doing their own screening.

Nova Scotia

Reporting

AIDS is reportable to the Department of Health
HIV + is reportable to the Department of Health

There is a non-nominal system of testing if it is wished (the laboratory specimen is coded). However, if the test is positive, the name must be given to the Department of Health.

Laboratory

Specimens are sent for testing either to the Victoria General Hospital (Halifax) or the Halifax Infirmary laboratories.

Tests

The ELISA screening test confirmed by the WESTERN BLOT method is used.

Counselling

The Medical Society of Nova Scotia (in consultation with the Department of Health and Fitness) produced "Information for Physicians on the HTLV III Antibody Test" in October 1986, which strongly advocates both pre and post test counselling.

Contact Tracing

Contact tracing is usually carried out either by the private practitioner or Public Health Unit, although some people who have tested HIV seropositive have elected to do it personally. Ultimately it is the responsibility of the local Medical Officer of Health to see that it has been attempted.

There has been no legislation concerning informing a third party that a contact is HIV seropositive. The ethics of disclosure have been discussed broadly, but no definitive steps have been taken to clarify the legal issues.

Insurance Companies

There has been no difficulty over insurance companies wanting to do their own screening.

Surveillance

The Department of Health records names of individuals who have AIDS or are HIV seropositive. The Director of the local Health Unit follows up on the details of name, age and risk factor if the form is not completed by the physician.

There have been about 150 people who have tested HIV+ up to June 1988.

Ontario

Reporting

AIDS is reportable to the Ministry of Health
HIV+ is reportable to the local Medical Offices of Health

There is a system of non-nominal testing, but there is also a choice, and about 40% of all specimens sent into the Central Public Health Lab use the name, the rest are in code. Normally AIDS is reported under the initials of the patient on the Federal LCDC report form, unless it is chosen to identify the name. An HIV+ result is recorded on the lab form either by the use of the name, the initials or a coded number, and gives the city of residence, birth date, risk category and symptoms.

There is a legislative clause which requires laboratories to report certain communicable diseases to the local Medical Officer of Health. This is not new legislation, but it is intended to normalize the existing legislation.

Laboratory

All specimens are sent for testing to the Central Public Health Laboratory, but there is so much demand that some satellite labs, such as in Ottawa and Kingston, are taking some of the load. Three universities have also been given permission to do a rapid ELISA screening test of patient's donations, tissues and organs.

The Red Cross screens in Toronto.

Tests

The ELISA test is used, confirmed by either the WESTERN BLOT, IFA or RIPA method.

Counselling

When the antibody test became available in 1985, the Provincial Advisory Committee on AIDS booklet on testing was sent to all physicians and some volunteers. This is a guideline,which highly recommends both pre and post test counselling, and stresses the need for informed consent.

Counselling can be done through the private practitioner; or there are also thirty-nine STD and Family Planning Clinics which arrange for it, or people can also chose to have AIDS counselling in a hospital. It is a government policy to make testing easy of access.

Health unit staff are working closely with physicians to ensure that people who test HIV seropositive receive follow-up counselling.

Contact Tracing

Contact tracing is either done through the physician or the Public Health Units, but ultimately it is the responsibility of the Medical Officer of Health to ensure that it has been attempted. A person who has been infected with the AIDS virus does not have the obligation to say who has been a sexual contact. A contact is never given an identifiable name.

It is legislated that a doctor does not have the right to inform a spouse that her/his partner is infected with the AIDS virus, without the patient's consent. This has caused some tension among physicians. It is also the physician's responsibility to try to convince the AIDS patient of the advisability of informing either contacts or spouse that they have been exposed to the AIDS virus.

Money was given to the Health Units for contact tracing, as well as education, to ensure that it would be carried out.

Insurance Companies

There has been some difficulty with insurance companies. Some testing is being done south of the border in the U.S., but there has been poor quality control, and the very quick turn-around time has involved a disproportionate number of false/positive results. Some companies have tested clients without their knowledge, and with no pre or post counselling, and this has led to some traumatic experiences. It is not illegal for insurance companies to do this, because the nature of their business is to be discriminatory. However, the Canadian Life and Health Insurance Association has issued guidelines to try to initiate consistent practices within the industry.

Negotiations are underway with the industry.

The situation is being discussed by the Federal/Provincial/Territorial Committee on AIDS.

Surveillance

A registry is kept of HIV seropositive cases. The Risk Factor is requested on the serology requisition form, but there has been a difficulty in that this is not always completed.

There is likely to be some duplication. Over 7000 specimens a month are being processed, and this has put some stress on the public health lab.

As of Feb 29, 1988, 4071 individuals had been reported as HIV seropositive, 67 of whom were women.

Prince Edward Island

Reporting

AIDS is reportable.

HIV + is reportable by name.

There is a nominal system of reporting. The name is reported to the Chief Health Officer, Department of Health and Social Services. A code is used so that the Laboratory does not know the name, but the physician is obliged to report it to the Medical Officer of Health (MOH).

Laboratory

Specimens are sent to Halifax, Nova Scotia for testing.

Tests

The ELISA screening test confirmed by the WESTERN BLOT method is used.

Counselling

The physician has the option of doing his own counselling, and taking on the care of the PWA. In both cases so far the physicians elected to do their own counselling and follow-up. If they had not wanted to, the Department of Health would have done so. There have been anonymous calls about testing, and these people have been advised to contact their own physician.

Contact Tracing

This is done by the physician with the support of Public Health if required.

Surveillance

A registry is kept of HIV seropositive persons. (5 persons as of Sept. 1987) The Risk Factor is obtained through the Provincial Health Department telephoning the physician who ordered the test.

Quebec

Reporting

AIDS is reportable
HIV + is not reportable.

There is a non-nominal system, only a number is used. A short notification form is sent to Communicable Disease Control, Community Health Department, where completion of the case report forms and other necessary investigation is undertaken.

Laboratory

HIV + specimens are sent to the Public Health Laboratory at Ste. Anne de Bellevue. The lab received substantial extra funding, but it has not been necessary to build extra facilities.

Tests

If the ELISA test is positive, the specimen is sent to the lab for confirmation by the IFA test and then the RIPA test if required.

Counselling

Counselling is given both before and after the results of the test are known, either by the private physician or through medical health teams if this is wanted.

Contact Tracing

Contact tracing is done through the person who has been tested HIV seropositive, or through the physician.

Insurance Companies

Insurance Companies are not allowed to establish their own laboratories.

Private Laboratories

There was a problem with private labs offering rapid test results, and the Province was asked to supply the Federal/Provincial/Territorial Committee on AIDS with a list of all labs designated for testing.

Surveillance/Research

HIV+ is not reportable in Quebec. Seroprevalence studies which are being planned, or are in progress, include surveys among Montreallers of Haitian origin, male homosexuals, a survey of women and men presenting at STD clinics, a study of women in prisons, and a province-wide survey of women of childbearing age.

Saskatchewan

Reporting

AIDS is reportable
HIV+ is reportable by name.

There is a nominal system of reporting. Results are sent to the regional Medical Health Officer and the Director of Communicable Disease Control.

Evidence of HIV infection was made reportable as of January 22, 1988. Anonymous laboratory requisitioning is still permitted. Whether the physician codes the information for the laboratory depends on the doctor's own decision. However, the referring physician must provide full identification if the results are positive.

Laboratory

There is one Provincial Laboratory in Regina that does all the testing.

Tests

Two screening tests are done by the ELISA method, and then positive tests are confirmed by the WESTERN BLOT method.

Counselling

Each physician is responsible for counselling and follow-up, in consultation with the local Medical Health Officer, who will provide assistance where necessary.

People who want to be tested can either go to an STD clinic or to their own physician. All physicians received guidelines about testing and counselling. It is recommended that the client is given both pre-test counselling and post-test counselling.

Contact Tracing

Contact tracing is co-ordinated by the physician, with assistance from the Medical Health Officer on request.

Isolated Areas

People in isolated areas go to their own doctors.

Insurance Companies

Insurance companies are establishing their own policies.

Research

The University of Saskatchewan is attempting to develop improved HIV diagnostic tests, in conjunction with other research groups outside the province.

Yukon

Reporting

AIDS is reportable
HIV + is not reportable.

There is a non-nominal testing system, and all data is coded. All testing is done through the Communicable Disease Officer, who draws the blood for testing and controls all the records. These are kept with utmost secrecy, and if she is away no tests are carried out until she returns. She does not contact clients' doctors; they phone in personally for their results.

Laboratory

All specimens are sent to British Columbia for testing.

Tests

The ELISA test is used, confirmed by the WESTERN BLOT method.

Counselling

The Communicable Disease Officer does all the counselling, and the depth to which she goes depends on who it is. She uses her own judgment, and finds that many people are very well informed. She counsels people in sexually transmitted diseases as well.

She is personally in contact with physicians ordering tests.

One of the conditions of testing is that the person has to agree to have a doctor informed if it comes out positive. There has been no difficulty over this.

Contact tracing

People who have tested HIV positive are asked to do their own contact tracing. If the HIV+ is reluctant to do it, the private physician is usually asked to help. She has found people to be very responsible and positive, and that most people care very much about transmitting sexually transmitted diseases to others.

Insurance Companies

Insurance companies have not requested their own testing facilities in the Yukon.

Summary

National

On the national level, a major document was prepared through a Health and Welfare Canada NHRDP grant, by Margaret Somerville and Norbert Gilmore. The recommendations of this report were approved by the National Advisory Committee on AIDS (NAC-AIDS) in December 1987, and they were subsequently adopted in principle as a "framework document" for studying the HIV antibody testing issue by the Federal/Provincial/Territorial Committee on AIDS.

The report makes the recommendation that HIV antibody testing should only be mandatory for all blood, organ, tissue, ovum and sperm donors, and that it is unwarranted to institute mandatory or compulsory HIV antibody testing for any individuals, groups, organizations, institutions or populations in Canada at this time.

It also makes recommendations about the ethical, social, legal and economic implications of testing, including concerns about counselling,contact tracing, confidentiality, human rights, psycho-social stress and false-positive results, among others.

The need to maintain the highest ethical standards in dealing with all aspects of testing and surveillance for the HIV antibody was repeatedly stressed throughout the report.

It also stressed that, although the specific recommendations in the report have been approved by NAC-AIDS, "all other statement" are those of the authors, and do not represent these of NAC-AIDS, the Minister of National Health and Welfare of Canada, or any other organization, agency or institution, and "Furthermore, anyone using this report should recognize that it is not intended to be final body on HIV antibody testing in Canada". (Preamble)

Provincial and Territorial

The following details were obtained from the provinces and territories:

AIDS is reportable in all provinces.

HIV + is reportable in:
Alberta, Manitoba, NB, Newfoundland, NWT, NS, Ontario, PEI, Saskatchewan.
Nominal report: NB, NS, PEI, Saskatchewan.
Non-nominal report: Alberta, Manitoba, Newfoundland, NWT, Ontario.

HIV + is not reportable in:
Quebec, Yukon, BC (qualified).

Laboratory Facilities

New Brunswick - specimens sent to Halifax, NS
Newfoundland - one provincial laboratory
PEI - specimens sent to Halifax, NS
Quebec - one provincial laboratory
Ontario - one provincial laboratory
- satellite labs in Ottawa and Kingston
- 3 universities do rapid ELISA screening tests on tissue

Alberta - two public health laboratories
- one private laboratory

Manitoba - one provincial laboratory
Saskatchewan - one provincial laboratory
Yukon - specimens sent to Vancouver, BC
NWT - specimens sent to regional laboratories in the south
BC - one provincial laboratory (which also cultivates AIDS virus)
NS - two provincial laboratories

Insurance Laboratories

Ontario - some insurance companies have been sending specimens for rapid testing to the USA, which has been unsatisfactory because of poor quality control. Negotiations are being made to send testing to provincial lab.
Manitoba - Great West Life is sending tests to USA. This is being discussed at federal/provincial level.
BC - It is suspected that a private laboratory has been established without permission or clearance. This is being investigated at the federal/provincial level.

Tests

ELISA confirmed by WESTERN BLOT:

NB (through Halifax, NS)
Nfld (screens for seropositivity, sends HIV + to Halifax, NS for confirmation)
PEI (through Halifax, NS)
Alberta, Saskatchewan, Yukon, NWT, BC, NS.

ELISA confirmed by IFA:

Manitoba

ELISA confirmed by IFA (and RIPA if required)

Quebec

ELISA confirmed by WESTERN BLOT, IFA or RIPA

Ontario

Testing

Through private physicians: all provinces
Through STD clinics: Nfld, Quebec, Ontario, Alberta, BC
Through Infection Disease specialists: Alberta, Manitoba, Yukon
Through Medicentre: Saskatchewan
Through government clinics and nursing stations: NWT
Through Maine, USA: NB
Through Health Units: Ontario, BC
Through Family Planning Clinics: Ontario
Through Reproductive Health clinics: NB

Counselling

Emphasis stressed on both pre-test and post-test counselling:

All provinces and territories.

Guidelines and/or information distributed to private physicians:

Nfld, Ontario, Alberta, Manitoba, Saskatchewan, Yukon, NWT, BC (where there is also a "Travelling Road Show" for general practitioners which may become a national model).

Contact Tracing:

Through private physicians and/or person who is infected: all provinces/territories.
Mandatory: NB
Through STD Control: Alberta, BC, Nfld, NB, NWT
Through nurse or support group: Manitoba
With help of public health: Nfld, PEI, NB, Ontario, NS
Public Health will only assist if requested by physician: Saskatchewan

Surveillance

New Brunswick	- Cases reported to provincial Dept. of Health
	- Risk factor and demographic information collected on a serology requisition form
	- Identification # unique, includes region and year
Newfoundland	- Registry of cases
	- Risk factor obtained by Health Dept. phoning physician
	- Identification through health care insurance # and initials of individual
PEI	- Registry of cases
	- Risk factor obtained by Health Dept. calling physician
Quebec	- HIV + not reportable
	- Study of Haitians, male homosexuals, women presenting at STD clinics and women in prisons
Ontario	- Risk factor requested on serology requisition form
Alberta	- HIV + not reportable
	- Study of women presenting to STD clinic

	- Plans to maintain surveillance of incidence, and prevalence of HIV infection, AIDS and ARC, and to evaluate the effectiveness of education and risk reduction activities
Manitoba	- Risk factor is requested on the Laboratory Requisition Form - Patient Code # includes last two letters of mother's name and one other number - Seroprevalence study of high-risk individuals
BC	- HIV + reported to STD Director by lab - Risk Factor required on the serology requisition form
NS	- Registry of cases - HIV + reported to Director of local Health Unit by physician

Personal Medical Costs

Overview

AZT

A major focus of medical costs has been the expenses connected with the provision of the drug AZT (Azidothymidine). Initially it was provided free of charge by the manufacturer, but as of May 1987, it has had to be paid for. Burroughs Welcome recently reduced the price by 20%, but it is still between $800.00 to $1000.00 per month per patient, or $250.00 Canadian per bottle of 100 tablets. Once started, many of the patients may have to continue on the drug for the rest of their lives. It has been found to prolong life as much as an estimated three years, and it also improves the quality of life for AIDS patients, but once there is a serious deterioration of health the termination of life is very rapid.

There is a major concern that other drugs that have been developed for AIDS have not been employed in Canada.

Arrangements for payment for the drugs vary from province to province, but the majority of provinces have agreed to pay for 100% of the costs of eligible patients.

Eligibility is established on a basis of the type of sickness involved (eg: pneumonia). There are identical criteria for a patient's eligibility in all provinces, and this was developed from an agreement between the federal government and Burroughs Welcome.

Arrangements for reciprocal billing has proved a potential problem, partly because of the mobility of patients between provinces, and partly because of a lack of universality among the provincial drug programmes. For example, in Manitoba, an AIDS patient from BC was treated with AZT at the out-patient clinic, but under the current inter-provincial billing agreement the allowable recovery was $46.50 per out-patient visit. A mechanism similar to the recovery of chemotherapy drugs would have alleviated this particular difficulty, and it was recommended that an agreement be worked out where the rate would be based on the actual costs of the drug.

The use of the Canada Assistance Plan (CAP) has been explored as a means of sharing costs between the federal government and provinces and territories in providing social assistance to persons in need. Under CAP, need has to be established on the basis of a financial test which reviews the potential recipient's budget and resources. It is the fact of need, not the cause of need, which determines eligibility, and the Social Assistance departments must provide the service and incur the cost before CAP can become involved.

CAP might not be an acceptable mechanism for delivery of health services, as the provinces and territories would be required to amend their health insurance and social assistance legislation to enable them to receive federal financial assistance under the plan, and this is still being discussed.

Direct Costs

The Royal Society of Canada Report, "AIDS: A Perspective for Canadians" (April 27, 1988) reviewed the cost of the AIDS epidemic in terms of direct and indirect costs (Costs of the AIDS

Epidemic, p.8). It reports that direct costs for HIV-related expenditures amounted 0.3% of Canada's total health care expenditure in 1985.

The personal costs, including continuing care to HIV-infected persons, (in-patient and outpatient costs, drug costs, home-care and physician's costs) were approximately $75 million in 1987. Non-personal costs, (screening, counselling, education, administration and research) were about $54 million, or a total of $129 million in 1987. Projected costs for by 1992 for all AIDS expenditures are 1.2% to 2.1% of all health-care expenditures.

It was noted that although the personal direct costs are about $82,500 per AIDS patient per year, no comparative figures have been applied for other major diseases, and this requires further study.

The report estimated the cost of counselling to be about $13 million in 1987, and the cost of screening blood donors to be about $6 million.

Indirect Costs

The Royal Society report also commented on estimated indirect costs when a person dies prematurely, in terms of economic loss to society of the person's productive capacity, and estimated that the loss represents between $150 million, (or 0.3%-0.6% of Canada's gross domestic product). It calculated morbidity at an average of $22,000 per person per year, or cumulative costs of mortality range from $300,00 to $1,000,000 per persons aged 20-29 years.

The Costs of Personal Trauma

Added to these estimates are the personal costs of loss of employment, revenue, housing, education, insurance, business revenue, and disability, pension and compensation benefits (Somerville and Gilmore Report "HIV Antibody Testing in Canada, Section I, p. 33).

Alberta

Individuals will not be charged for medical services provided they are eligible. Most people are covered by Blue Cross insurance.

The Province pays for AZT.

British Columbia

People who are on Social Assistance have the cost of AZT completely paid for, as well as all their other drugs and treatment.

Others pay into the Universal Pharmacare Programme, and contribute 20% of the total cost up to a set limit. The limit for AZT is $2,000.00 per year. If PWA's have money or a job they are billed. There is very strong feeling about this, and many people are not paying when they are charged, and the government is not pursuing this. The costs are so high, that many people feel they are close enough to Social Assistance that the government should pay for it all.

The cost of other types of treatment comes under Medical Insurance. There is no charge except for out-patient expenses, and under Pharmacare the patient would be billed 20% up to a certain limit.

The extra cost of caring for AIDS in hospital is covered by the Ministry of Health.

Manitoba

AZT is provided at no cost to patients under the Pharmacare special drug programme.

Other drugs are provided under the Pharmacare program which covers 80% of drug costs after an initial deductible. In-hospital drugs are free of charge.

New Brunswick

Medical care is fully covered in the province through the Department of Health Medicare Program and includes situations where a New Brunswick patient goes to Nova Scotia, or elsewhere out of province, for treatment.

AZT is covered by the Province. Access to the drug is dictated by the distribution/research protocol. The provincial epidemiologist and a medical specialist based in Fredericton are responsible for controlling the distribution of AZT in the province.

Other drugs are not automatically covered unless the person fits under the Senior's Prescription Drug Program or is a recipient of an income (social) assistance drug card for some other extenuating financial circumstances.

Although medical expenses are paid for by the province, New Brunswick PWAs have been subjected to financial stress because of the high cost of travel and accommodation when they have to make frequent trips to be monitored at the Victoria General Hospital in Halifax. None of this is paid for, and it can cause severe anxiety and hardship. Some have expressed that they have found the MACAIDS group in Halifax to be very supportive and humane in helping them deal with this aspect.

Newfoundland

Hospitals services are free in Newfoundland, and the Province covers the cost of AZT.

Additional costs depend on the situation. Many patients have their own Health plan or personal insurance. If not, they may have to meet their own expenses.

Alternatively, if the individual does not have enough funds to meet expenses, Social Services can assess the cost of care compared to the personal income of the patient. If there is not enough to provide a reasonable income, the patient can be classified as "medically indigent" and can receive assistance from social services.

Northwest Territories

There is nothing specifically in writing about AZT, but there is a very comprehensive Pharmacare programme.

The issue of who will pay for AZT is soon going to be reviewed by the Executive Council of the government.

Native health care benefits are quite comprehensive.

The cost of AZT would be covered for Welfare recipients.

Medical costs are covered by Territorial Health Insurance.

There is also a very transient population, and when transient people get sick they usually return home. Most non-native people in the Territory have come from Southern Canada. Costs would then depend on the area they returned to, the local health insurance policies involved, and whether there was a portability clause in their private plan, if they had one.

Nova Scotia

Hospital services are free in Nova Scotia.

The provincial government covers the cost of AZT through the administration of the Victoria General Hospital. There are approximately 30 people receiving this drug currently as part of an open trial.

Other drugs are provided through Pharmacare, a program for disabled recipients of Family Benefits. Clients in receipt of Municipal Social Assistance may qualify for Pharmacare coverage as determined by the municipalities.

A person with AIDS would need to meet the usual eligibility criteria.

The average cost of drugs, over and above the cost of AZT, is $100.00 - $200.00 per patient per month.

Ontario

The Province pays the full cost of AZT. This comes out of the hospital fund.

The government has provided annual funding and one-time capital grants to operate FACSan analyzers to perform T4 cell counts on patients infected with the AIDS virus. This is used both to monitor patients and as a requirement for AZT drug treatment.

Most AIDS patients are young and do not have an adequate (or any) employment insurance package. If they are poor enough to be classified as welfare recipients, all their expenses are paid for through this.

Prince Edward Island

Hospitals are free.

The Pharmacare Plan would cover the cost of drugs. At this time this plan is for Seniors and Social Service clients and not for people with AIDS, but something might be worked out.

Expenses outside hospital are not covered, but some sort of arrangement could probably be made.

Trips to Halifax would only be covered if the PWA was on Social Assistance.

None of this has become an issue yet.

Quebec

There are no policies to bear the cost of drugs for AIDS patients, except for AZT, which is completely paid for by the government.

Patients must bear all other costs, either out of their own pocket or through insurance, unless they are on aide sociale.

Saskatchewan

General medical and hospital costs are fully covered. Drugs are covered by the Prescription Drug Plan. The Plan pays 80% of the cost of drugs, once a family has reached the deductible of $125.00 per annum. However, the province does pay 100% of the cost of AZT.

Yukon

AZT would be provided free of charge through the Territorial government.

Hospitals are also free.

Anti-HIV testing expenses are covered by the Federal Government Public Health Program.

Summary

Direct costs of medical care amounted to a total of approximately $129 million in 1987. This includes in-patient and out-patient costs, drugs costs, homecare, physician's costs, screening, counselling, education, administration and research.

Indirect costs represent a loss of $150 million in terms of lost productivity.

Individual costs:

AZT

AZT completely paid for by province

NB, Nfld, PEI, Quebec, Ontario, Alberta, Manitoba, Yukon, Nova Scotia, Saskatchewan

Cost of AZT being reviewed

NWT

Person with AIDS pays a proportion of the cost of AZT

BC

Other drug expenses

Drugs other than AZT paid for by the province (maybe with deductible):

PEI, Manitoba, Saskatchewan, Yukon, NWT

Person with AIDS pays total cost of other drugs (unless on Social Assistance or insurance plan)

NB, Nfld, Quebec, Ontario, Alberta, NS

Person with AIDS pays some of medical costs

NB, PEI, Alberta, Yukon, BC

Social Assistance

Most provinces also commented that, as so many people with AIDS are young, and their employment has been affected, or they have had no chance to invest in an insurance plan, they may qualify for Social Assistance on the grounds that expenditures for medical costs outweigh income, making them "medically indigent". Under these circumstances, all costs are paid for by the province or territory.

Hospital expenses

These are provided free.

Travel Expenses

The cost of travel to and fro from New Brunswick to Halifax was said to cause much financial hardship to PWA's as no incidental costs are covered. The same point was raised of PWAs in Nova Scotia who live at a distance from Halifax.

Federal/National

On May 1, 1986, the Minister of Health and Welfare announced a $39 million five-year program for AIDS issues, which comprised the following elements:

The National Advisory Committee on AIDS (NAC-AIDS)

The National Advisory Committee on AIDS played a significant role in advising the Minister of Health and Welfare on AIDS issues prior to the establishment of the Federal Centre for AIDS, and has also continued its activities since. "Now in its fourth year, NAC-AIDS provides expert advice and recommendations to the Minister on the whole spectrum of AIDS issues. The chairman is Dr. Norbert Gilmore, Royal Victoria Hospital, Montreal. The secretariat is provided by the Federal Centre for AIDS." (Note from Mr. Greg Smith, FCA, Dec. 1987 to the N.S. Task Force on AIDS).

Federal Centre for AIDS

In 1985, the House of Commons Standing Committee on National Health and Welfare was established to enquire into the AIDS epidemic in Canada. After a year of holding public hearings, it made its report to the government in May 1986. Its findings included the observation that Federal programs were somewhat unco-ordinated in dealing with AIDS, and led, among other recommendations, to the formation of the Federal Centre for AIDS in Ottawa (Recommendations 1 & 3). Its principal purpose when it was established was to co-ordinate federal programs. Its services expanded very rapidly, and its staff tripled within the first year.

"The role of the Centre is to plan, direct and co-ordinate federal government activities under the National AIDS program. Part of the Health Protection Branch of Health and Welfare Canada, the Centre encompasses: laboratory and field research activities; clinical trial co-ordination for new AIDS drugs and vaccines; surveillance of AIDS and HIV infection in Canada; international and intergovernmental liaison, advisory and other support services to health and social services, public and private enterprise; and the development of AIDS education programs. The Centre is supported with a $4 million budget." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS, and Summary Notes of Meeting with Greg Smith by Dr. W.A. MacKay, N.S. Task Force on AIDS, Dec. 7, 1987).

Among other interests, the FCA has established an important central resource centre for AIDS materials from all over the world, and encouraged the provinces and territories to contribute what they have developed.

An LCDC Electronics Board details statistics, AIDS conferences, notices and reports, and is also available to the media. (Laboratory Centre for Disease Control; the FCA was formed as a unit within LCDC).

The FCA is developing a national database for AIDS and AIDS-related issues (Advisory Committee for AIDS, Feb. 1988, 4.5) and will be working with the provinces and territories to establish local co-ordinators and a national network of information.

There has been a proposal to establish a national hotline, linked to existing provincial hotlines (Advisory Committee for AIDS, Feb. 1988, 4.9) and a national magazine on AIDS (Advisory Committee on AIDS Feb. 1988, 4.10) but the funding for these is still being debated.

The Federal/Provincial/Territorial Advisory Committee on AIDS

"This forum provides a means of planning and co-ordinating the activities of both levels of government, to ensure consistency and effectiveness of response." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS). A number of sub-committees have been formed to study specific aspects of AIDS issues.

The National Health Research and Development Program (NHRDP)

"The National Health Research and Development Program (NHRDP) is providing $23 million to extramural researchers. This money is being used to fund work on all aspects of AIDS for: research studies; conferences; the development of research scientists in various disciplines. In-house research activities in the Federal Centre for AIDS supplement these efforts." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS).

The Health Promotion Contribution Program

The Health Promotion Contribution Program is providing $4 million funding for community-based AIDS organizations. "Community organizations play a vital role in providing education and services to: high risk groups; persons with AIDS; and the general public." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS).

The Royal Society of Canada's recent report, "AIDS: A Perspective for Canadians" (April 1988) also recognizes the significant role that has been played by community-based organizations in Canadian AIDS public education development, but at the same time stresses, "We believe, however, that greater and more co-ordinated efforts are needed." It also regrets the lack of inclusion of evaluation components, which has at times hindered the understanding of the effects of education programs, and whether there have been positive or negative effects as the result of such programs (pages 17-18, and Box 31).

Department of Health and Welfare Support for Diagnostic Capability

"The Department is contributing $4 million to the development of the Human Immunodeficiency Virus (HIV) isolation and culture facilities and services in Canada, including the training of technological personnel. The Federal Centre for AIDS also develops and tests diagnostic tests and reagents for HIV infection." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS).

Fifth International Conference on AIDS, 1989

"This annual international meeting will be held in Montreal. The conference will bring scientists and public policy leaders together to address the theme of global partnership in the search for solutions to the varied issues around AIDS." (Note from Greg Smith, FCA, Dec. 1987 to N.S. Task Force on AIDS).

The Canadian Public Health Association (CPHA)

Prior to the creation of the Federal Centre for AIDS, this non-governmental organization had been looked on as the vehicle for AIDS public education. It still maintains a leading role in this, as well as complementing education initiatives coming from the Federal Centre for AIDS.

In 1986, it was awarded a $3.7 million grant by the Department of Health and Welfare to develop an AIDS Education and Awareness program over five years, on a Canada-wide basis.

In April 1988, it released a sheet of background information on this important and comprehensive program:

> *Backgrounder* *April 14, 1988*
>
> *The Canadian Public Health Association*
>
> The Canadian Public Health Association (CPHA) is a voluntary organization dedicated to improving and maintaining personal and community health in Canada and abroad. Founded in 1912, the Association currently has a membership of more than 2,500 health professionals and private individuals brought together by a common commitment to improving the health of all.
>
> Among the many areas in which CPHA is actively involved are: family health; health promotion; gerontology; rural health; epidemiology and disease control; sexually transmitted diseases; health administration and environmental health and accident prevention.
>
> The $3.7 million CPHA National AIDS Education and Awareness Program was established in 1986 to enhance public knowledge of this fatal disease and thereby encourage its prevention. Funded by Health and Welfare Canada, the five-year program is headed by four full-time staff and a 10-member advisory committee.
>
> The program has three main objectives:
>
> > To prevent or eliminate the spread of HIV (Human Immunodeficiency Virus) infection, through education, awareness and behaviour modification.
> >
> > To educate and make the public more aware of accurate and up-to-date information on AIDS and HIV infection by promoting positive, healthy lifestyles to reduce risk behaviour.
> >
> > To improve the quality of life of the HIV infected individual through education and awareness.
>
> While a prime focus is on educating the general public, the program also targets specific priority groups, such as sexually active men and women at risk, the school system (students, teachers, boards), unions and service workers (Police, fire, personal service providers, managers). The problem of special high-risk groups, such as prostitutes and intravenous drug users, is also addressed.
>
> The program works with the many AIDS support groups at the community level providing assistance and information when necessary.
>
> To reach its objectives, the Education and Awareness Program is attacking AIDS on a number of major fronts.
>
> The Program operates a computer-based information clearing house that accesses AIDS information on a global level. More than 600 requests a month are handled by

the clearing house in the process of distributing AIDS posters, videos, brochures and other education materials to interested groups and individuals across Canada. A newsletter that provides factual information on AIDS from Canadian and international sources is distributed free to more than 7,500 persons and organizations involved with public health and AIDS information programming.

The Program also works with educators and health professionals to develop age-appropriate AIDS materials for use in the Canadian educational system. A research project was completed in October 1987 that was the first major comprehensive analysis of AIDS information requirements among educational jurisdictions in Canada.

Building on this research, the CPHA is now producing, in co-operation with Health and Welfare Canada, an AIDS print-video package for use in grades 11-13 across Canada.

In addition, CPHA has undertaken a number of other educational projects. A brochure, "The New Facts of Life," has been produced and is now into its third printing with more than 3 million copies in circulation.

A joint publishing venture was initiated with the Toronto Sun of the well-received "AIDS: What Every Responsible Canadian Should Know." This is a general AIDS resource book for professionals and the general public written by James Greig with an introduction by Dr. David Walters, director of the CPHA AIDS Education and Awareness Program. More than 100,000 copies have been sold to date and the book is going into its second printing.

A video/print package on AIDS and the Workplace has been co-produced with the Canadian Labour Congress and is in wide distribution across Canada.

To enhance target group awareness of AIDS and necessary preventive and supportive approaches in the community, a comprehensive media program has been developed. The initial campaign was launched in March 1987, with an appeal to all Canadians to "Learn the New Facts of Life" and join in the nation-wide "Attack on AIDS."

The objective of this campaign has been to mobilize broad sectors of society towards greater attention and understanding of AIDS. The campaign features electronic public service announcements and promotional print material such as buttons, posters and brochures, as well as media appearances.

The program helps to focus media attention on AIDS programming with on-going contact for comment/interviews, open line shows, news conferences and campaign updates. On a continuing basis these efforts have reached millions of viewers and listeners all across the country.

A major element of the CPHA program is development and co-sponsorship of conferences, seminars and public forums on AIDS education in Canada. The program has sponsored and participated in a large number of conferences, with frequent guest speaking appearances by the program director. Upcoming in May 1988, is a national AIDS education conference in Toronto, co-sponsored with Health and Welfare Canada and the Canadian AIDS Society and financially supported by the Canadian Life Insurance Industry.

The CPHA program has recently launched a major initiative to involve the private sector in AIDS information programming for youth, the general public, and high-risk groups, support for persons with AIDS, their families and close associates, AIDS in the workplace information, and research. Initial discussions have been undertaken with several companies and industries and a number of joint AIDS education and fund raising opportunities are currently under review.

Federal

Members and employees of the McGill Centre for Medicine, Ethics and Law are currently working on a number of AIDS-related projects.

The McGill Centre for Medicine, Ethics and Law is preparing a book entitled "Responding to AIDS in Canada". The text is one of the projects being undertaken as part of the Centre's "AIDS Research Program" funded by NHRDP. Publication will be in loose leaf form to allow updating on a regular basis. Publication is expected by the end of 1988.

The text is organized into separate sections, including one each for the Federal government and each of the provincial governments. Each government section is divided into five parts and outlines existing law of relevance to AIDS and looks at activities with respect to advisory bodies, policies and guidelines, education and funding. The book also includes an outline of the activity of community groups, such as the Canadian Public Health Association, the Canadian AIDS Society and the Canadian Haemophilia Society.

In addition, the text includes summaries of the policies of the municipalities of Vancouver, Toronto and Montreal and also presents examples of the response to AIDS by corporations in Canada.

The text is planned primarily to be a source of information in an easily accessible form. As a secondary purpose, the text will provide an opportunity for governments and organizations to examine the range of strategies that could be adopted. It provides a base line for assessing the response to AIDS in Canada to date.

AIDS-related projects include another book on autonomy and AIDS, a report on the recommended parameters for HIV antibody testing in Canada and a similar report on confidentiality of medical information. Ongoing projects address the economic impact of HIV infection and AIDS, the establishment of a computerized telephone AIDS information and counselling service, the analysis of a Minitel-like system as a tool in peer group counselling, the development of appropriate policies by school boards in Quebec and elsewhere, assisting child welfare and youth protection services throughout Canada to adequately address the issues posed by AIDS, the examination of ethical and legal issues involved with the use of experimental drugs and novel therapies, and the recommended parameters of an AIDS vaccine testing policy.

The Centre is also organizing two conferences of relevance. On November 6, 7 and 8 there will be a conference entitled "HIV and parenthood: the next generation" and on November 28, 29 and 30 a conference on "Economic Impact of HIV Infection in Canada". The proceedings of both conferences will be published.

National Exchange on AIDS, Drugs and Child Abuse

This national exchange with the Canadian educational communities is funded by Health and Welfare in the amount of $150,000 with an additional $29,500 of support from other national organizations in education. It will be held in Winnipeg June 5-8, 1988 and will address a policy agenda for these three major health topics with provincial/national leaders. Conference objectives are as follows:

- to provide an opportunity for an exchange among educational leaders, health and social services professionals, community representatives and government officials on critical and current aspects of the school's response to the three issues;

- to examine what is common about the responses to these three issues and how these responses relate to a comprehensive school health or personal/social development program;
- to emphasize and demonstrate how partnerships at different levels and between different groups are essential to a successful school response;
- to provide pre-conference reference material enabling participants to focus their discussions on specific issues in an inter-active conference format;
- to provide post-conference material assembling the best ideas about the issues into a "manual" of suggestions and resources.

Canada Youth and AIDS Survey

This Health and Welfare funded survey has been carried out by Queen's University. Through interviews with 40,000 youth, grades 7, 9, 11, and first year university, and 700 street youth, the findings will tell of the knowledge level, attitudes and behaviours of youth related to AIDS and sexuality. Release of the findings and provincial consultations are to commence October, 1988. There will be a national report as well as a report for each province and territory on their statistics. This is the most comprehensive survey on AIDS and sexuality in Canada to date.

York University - Adult Survey

A Canada-wide survey is being funded through National Health Research and Development Program to determine levels of knowledge, attitudes and behaviours of the adult population. The pilot study will commence shortly to test the survey tool.

Five Year Communications Plan

Development is underway for a communications plan for the federal government related to the Federal Centre for AIDS role in AIDS education and awareness. This plan will be broad and comprehensive but will look at segmenting and reaching targeted audiences through education and awareness programs with the possibility of including advertising initiatives.

This plan will not be completed or implemented until new dollars are committed for AIDS education.

Women and AIDS

The Federal Centre for AIDS has undertaken the development of a literature review and production of a directional paper on Women and AIDS. This paper will provide priority areas for program development related to this targeted audience. Also underway is the preparation of a public informational brochure for women addressing AIDS issues. A fall release is anticipated.

Learning AIDS - Video

This initiative is being undertaken in cooperation with the Canadian Public Health Association and the Program Advisory Committee for the AIDS Awareness and Education Program.

Due to requirement for additional Federal Centre for AIDS funding, beyond the annual program grant, a tender is being undertaken for the production and completion of this video. Tender submission will be reviewed May 25, 1988. Timelines and production schedules will be determined accordingly.

(From: Federal Centre for AIDS, Communications and Education Services, Education Programming Update Jan.-May 1988. Submitted by Barbara Jones, Chief, Communications and Education Services, FCA.)

Alberta

Goals

The Province began a three-year comprehensive program of community-based AIDS education in 1987. It is directed towards:

- the general public,
- high schools,
- resource materials for the Public Health professionals,
- on-going education for health professionals,
- a Hotline,
- people with risk factors.

It is being delivered by government and non-government organizations as well as by funded agencies and requires collaboration among existing agencies.

In October 1987, the Alberta Community and Occupational Health Department produced a program for the province entitled "Education and Caring: Alberta's Program for the Prevention, Management and Control of AIDS." It includes detailed projections and suggested goals, and is primarily concerned with the control of AIDS infection and how best to care for those who are infected.

A major health care plan, developed by an interdisciplinary committee on patient care, will be released in August 1988.

Personnel

The provincial program is headed by the Director. AIDS education is planned primarily by several interdisciplinary committees on AIDS education who work with the AIDS Program Planner. An AIDS in the Workplace Consultant is on staff with Occupational Health, and several Nurse-Educators have been added to STD control's Education Unit. Funding is provided to community AIDS organizations and to Health Units to continue their AIDS education activities.

Community Leaders

An important objective of the education plan is to reach community leaders through on-going education.

Training

Much of the training is carried out by the STD Control Unit nurse-educators, who make presentations to community groups, do in-services for health care workers and teachers, and also man the toll-free AIDS Info-Line. They average about 63 presentations a month.

The Speakers Roster of Health Professionals gives public seminars, and also plays an important part in AIDS education.

There is collaboration with many working groups.

There is a sense of urgency about the need to maintain a high level of public awareness about AIDS issues, and to secure an education level that will have long-term effects.

Programs

A comprehensive AIDS public education program began in 1987:

- Education packages were developed for health-care professionals.
- STD Education Unit staff provide educational sessions to community groups, health workers and other concerned groups, as well as teacher in-services.
- The proposed strategies contain eight components:

  1. Make people participating in high risk activities for HIV infection aware of their risk and their ability to modify their risk
     - media campaign using TV, radio, billboard, newspaper and bus advertisements.
     - messages will be four-fold and will address:
       1) the need to be aware of personal vulnerability to HIV
       2) that HIV testing is available and that persons engaging in high risk behaviour are encouraged to seek assessment (in Alberta, HIV infection is not reportable)
       3) that educational programs and support programs are available to promote reduction of high-risk behaviours
       4) how to contact these programs and services.
  2. Encourage people engaging in high risk activity to be assessed, counselled, and tested as appropriate, for the presence of HIV antibodies.
  3. Conduct "risk reduction" programs to change behaviours and reduce the chance of acquiring or transmitting HIV
     - to include one-on-one counselling, peer group counselling (AIDS Networks), and educational messages with recommended safe alternative behaviours to reinforce messages received through counselling.
  4. Ensure that sexuality education with an AIDS component is provided to all junior and senior high school students in Alberta.
  5. Provide public education to increase understanding and lessen fear about AIDS, including education programs in the workplace
     - a large part of this strategy will be efforts to link effectively activities at both the provincial and local levels
  6. Conduct education programs for physicians and other health-care workers to increase knowledge regarding transmission and infection control and to increase awareness of psycho-social issues and capability in caring for patients with HIV infections and AIDS
     - to include collaboration with the Medical Association and other organizations to incorporate AIDS content into undergraduate, post-graduate and continuing education.
  7. Maintain a surveillance mechanism of incidence and prevalence of HIV infection and AIDS, and evaluate the effectiveness of education and risk reduction activities.

8. Direct provincial research funding agencies to allocate funds for AIDS research.

(Summary from paper prepared by Maureen Summers, N.S. Task Force on AIDS, "Province-by-Province, Summary of AIDS Education Initiatives" 20-4-88)

Media

The three-year campaign is being conducted through TV, radio, newspapers, magazines, billboards, transit ads and brochures, among other avenues for reaching the public.

A special media program will be directed towards high-risk activities.

Standardization of information

The fact that the program has been planned in advance over the entire three years will help to maintain control and enable it to be well co-ordinated at every level.

Evaluation

Evaluation of the effectiveness of the mass media campaigns, school education and risk reduction programs has been built into the three-year plan.

The Province has been pleased with what has been accomplished so far. The Minister's statement, "Health is not a moral issue" has had an important effect in developing and building provincial attitudes and programs.

British Columbia

Goals

Immediate goals are to continue the very extensive public awareness campaign that commenced in September 1987 through the provincial Ministry of Health.

Personnel

There is one Provincial Advisory Committee for all AIDS issues, which advises the Minister of Health.

The Mayor's Task Force (Vancouver) has very recently filed its recommendations for a five-year plan for Vancouver City (April 25, 1988).

Community Leaders

The extent of the AIDS problem in British Columbia has necessitated the need for leader involvement.

Volunteers and Community-based Groups

There are no volunteers working with the government.

Community groups use volunteers, but maintain a core staff.

The Mayor's Task Force of Vancouver City has recommended AIDS Vancouver and the PWA Coalition to make the transition from volunteer groups to non-profit organizations, using the San Francisco experience as a model. The decision to fund or not to fund will depend on the group's demonstrable financial stability and its programs.

Training

Ministry of Health employees have participated in numerous workshops, symposia and in-services. Training programs are constantly being up-dated to meet changing needs.

All Health Units received a copy of an AIDS educational video to be used for public presentations.

Programs

An extensive provincial public awareness campaign began in September 1987

- It coincided with the launch of the new school curriculum, September/November.
- Public service announcements (TV) concerning AIDS ran September/November.
- Two pamphlets and information on AIDS Hotline number were mailed to all households in B.C. One pamphlet gave general information on AIDS, the other was entitled "Talking with your children about AIDS – A Parent's Guide."
- Radio, TV and bus posters were produced.
- An STD AIDSline for information, counselling and support (but primarily for information) was instituted. This is quite different from the Hotline.
- A pamphlet series was produced.
- A video in English, Cantonese, Hindi and Punjabi was made available to the public.
- The Family Life Education curriculum became mandatory in grades 7 to 12.
- Ministry of Health employees participated in radio and TV shows and hospital presentations on AIDS. Over 100 newspaper articles and 50 radio and TV appearances or interviews were held (up to September 1987).
- A booklet was written for physicians.
- A yearly symposium was planned for physicians.
- Travelling workshops were arranged for general practitioners.
- Dr. Rekart's monthly column in the B.C. Medical Journal will continue to be produced.
- A workplace package was produced.
- A preliminary program for prisons, concentrating on education and testing, was initiated.
- A pilot education program for Native Indians is being tested in the field, and the results have not yet been returned.

- A nurses-on-the-street program started in January. It involves education, counselling, testing, referrals, and the provision of condoms and bleach bottles with instructions on how to use them.
- The Ministry of Health is developing guidelines for dealing with AIDS in the workplace (chairing an interdisciplinary committee).
- The Ministry of Health is developing an AIDS resource centre on the Lower Mainland, which will have up-to-date medical and statistical information as well as general reading material and information on various issues related to AIDS.
- The Mayor's Task Force on AIDS (City of Vancouver) is initiating a five-year plan which will be complementary to provincial and federal AIDS programs and primarily concerned with community support services and the co-ordination of federal, provincial and municipal funding efforts on AIDS in the City of Vancouver.

Media

There are no universal guidelines for the media. No government employees give out information except for one designated spokesman, the STD Control Director. He deals with all information, news releases and details of conferences.

Any misinformation is dealt with by the Director of STD Control personally. He will usually call privately and try to avoid a public confrontation.

Standardization of information

All information goes through the office of the Director of STD Control, including private materials.

Pamphlets are usually produced in green/blue colours, but for AIDS, harsh colouring like black and red has been found to be more effective in making people reflect on the seriousness of the message (that it is a deadly disease).

Evaluation

Evaluation and revision is continuous.

Prior to the Public Awareness program, focus group interviews were carried out and then repeated with the same group afterwards. This was a qualitative evaluation rather than a quantitative one, and it was thought afterwards that a quantitative study might have been more satisfactory.

The strong message which came out of this study was the need to continue with educational programs, and not to ease up. It has been found that people in general very soon forget and become complacent about taking safety precautions.

The Province has been satisfied at the way an immense job has been tackled, but it is at a crossroad in having to take stock and initiate programs which will continue for at least ten years. Nothing has been cancelled to date, but information, approaches and the success of initiatives have to be weighed and up-dated. The Mayor's Task Force (the City of Vancouver) has been an important part of that procedure.

Manitoba

Goals

An AIDS public education campaign was undertaken in the fall of 1987. Phase II of this campaign is in the planning stages.

Targets include:

- general public – mass media
- teachers – in-services
- health professionals – in-services
- the workplace
- individuals/groups associated with risk activities.

The intention has been to increase an understanding of HIV infection; to decrease public anxiety; to deal with issues as humanely and compassionately as possible, and to eliminate the spread of infection.

Personnel

There is an Inter-departmental Committee for AIDS, a provincial Co-ordinator for AIDS, and a Health Educator.

The Inter-departmental Committee consists of a wide range of government departments, including the departments for the Workplace, Safety and Health, Education, Northern Affairs, Worker's Compensation, the Attorney General's Department, Community Services and Corrections, and also the Alcoholism Federation of Manitoba.

An AIDS Education Council has been established by the Ministry of Education.

Leadership is provided by Manitoba Health.

Community Leaders

There is no specific program directed towards community leaders in general, although leaders in the immigrant/newcomer communities are being mobilized.

Volunteers and Community-based Groups

There are no financial incentives to organize volunteers, but organizing volunteers is an activity of Community Health Centres, particularly the Village Clinic.

Training

There has been a major effort on the part of the Department of Health to develop programs to provide trainers for AIDS.

Manuals of AIDS information have been developed, but not training manuals as such. They are available with packages for developing in-services, and provide standardized information.

There have been in-services for public health nurses and counsellors to provide counselling and information sessions to individuals and groups on AIDS and HIV infection.

Programs

A province-wide public awareness campaign began in the fall of 1987.

- It included production and distribution of a pamphlet on AIDS information, "AIDS: Know Enough to Protect Yourself – Fast Facts." It stressed that "AIDS is everybody's business."
- A poster was produced, identical to the pamphlet cover, repeating the message and advertising the AIDS/Info-line.
- A Hotline was established to deal with questions about AIDS and to recommend resource material and support groups for AIDS patients and their families.
- A booklet was produced for health care givers, "Information Update for health care providers: Human Immunodeficiency Virus."
- A series of guidelines on workplace prevention and management of AIDS and HIV infection were produced.
- An AIDS education curriculum was placed in schools as of September 1987.

Standardization of information

The government has produced pamphlets and posters, and a number of booklets for health care providers and the workplace.

The Manitoba Education Council on AIDS reviews all curriculum materials.

Evaluation

The Province has been reasonably satisfied with its achievements.

Programs are evaluated both before and after they are undertaken. This was done before the mass media campaign, and will be done again before Phase 2.

New Brunswick

Goals

There is no formal public education program for AIDS in New Brunswick.

Personnel

Educational activities are carried out on a number of fronts. Within the Community Services Division, regional offices may have individuals who have been specifically assigned the task of coordinating education activities. Medical Officers of Health, Public Health Nursing staff and staff of Reproductive Health Clinics may be involved in presentations, information distribution and direct counselling. Staff in the field are supported by one Nursing Consultant and the Chief Medical Officer of Health, centrally.

In addition to the educational activities carried out by Public Health staff, AIDS New Brunswick, a community-based organization, is involved in education, counselling and support.

The Board of AIDS New Brunswick has representation from Public Health central office, and several members are associated with Public Health field offices or hospital activities.

Community Leaders

Public Health field staff and the AIDS New Brunswick members are trying to stimulate the development of community-based groups and therefore promote AIDS education.

The Minister of Health is aware of issues surrounding AIDS, and he recently announced in the Legislature that some funds would be directed towards AIDS education activities.

Volunteers and Community-based Groups

AIDS New Brunswick is the only province-wide community-based group focused specifically on AIDS. There is also an AIDS committee in Saint John and a group has been founded in Moncton. In addition, organizations such as Planned Parenthood have been involved in presentations.

A Buddy System has been found to be very supportive.

There are 43 volunteers manning the Hotline.

Training

There has been a wide variety of talks given by physicians and public health workers, and a number of in-services have been provided (including for teachers). There have also been formal seminars.

The AIDS Co-ordinator has only been in office for a few months and, because of the pressure of work priorities, does not solicit speaking engagements although she will respond to requests.

Programs

Several symposia have been held in the past, including one major one by the Canadian Public Health Association in 1986.

Public Health staff have been involved in a number of in-services for the Department of Education, Extra Mural Hospital and other continuing education activities.

Guidelines have been developed for the general public, health care workers, groups associated with high risk activity, and some specified occupational groups, giving standardized information on awareness and education programs.

A Hotline was established.

A curriculum for school educational programs was developed.

Media

There has been no specific media program developed as yet. This may be established over the coming year.

Standardization of information

Information is presented to the public through a limited number of sources. Epidemiological information has been standardized and is published regularly in the Epidemiological Bulletin published by Dr. Chris Balram.

The Department of Health developed guidelines for standardized information and awareness education programs for health care workers, the general public, specified occupational groups and groups associated with high risk behaviour.

There are only two AIDS New Brunswick spokespeople on AIDS-related matters, the AIDS Co-ordinator and the President of AIDS New Brunswick. Any public press release has to be approved by either one of them. Volunteers are not allowed to discuss anything with the media.

The composition of the Board of AIDS New Brunswick is a check on misinformation. There is a mix between a variety of professionals and the gay community, and the representatives are well aware of new events and information. If there did happen to be an error that needed addressing, the AIDS Co-ordinator would make a response in writing.

Evaluation

There has been no formal evaluation of the effectiveness of current activities. The province will be looking to Canada-wide surveys which have been carried out to examine knowledge, attitudes and behaviours.

Newfoundland

Goals

The goal of the Newfoundland AIDS education program has been to reach as many people as possible, to provide information, to allay fears, to prevent the transmission of the disease, and to emphasize responsible decision-making.

A public education campaign was initiated in 1987. The public education campaign offers education and information on AIDS to the public in general, and specific target groups are given special attention.

It is also intended to do an evaluation this summer (1988), to look back over the past year and to determine the direction for the future.

Personnel

AIDS public education is primarily dealt with through:

- the Department of Health public health staff (public health nurses, inspectors, medical officers of health, health educators),
- the Public Health Nurses and inspectors in each of the five administrative areas include AIDS education "on the job" (e.g. mall displays, group presentations, newspaper articles, Cable TV, oral discussions),
- the AIDS Public Education Committee in each of the five Public Health Regions,
- Health Inspectors – food handlers, personal service workers.

Community Leaders

Regional AIDS Public Education Committees and Public Health Nurses in communities have contacted community leaders as a component of the AIDS public education program.

Volunteers and Community-based Groups

There are no financial incentives to encourage volunteers. The Department of Health prefers to maintain control of programs at this time, although consideration is being given to funding a small local group working with targeted gay groups.

There is very little community group involvement, although the Newfoundland Labrador AIDS Committee, a community-based non-profit organization and a member of the Canadian AIDS Society, was formed recently.

Training

There are programs to "train trainers" through the Public Health system, but no manuals have been developed specifically for this.

Programs

There have been successful public forums and mass media public awareness campaigns, using the slogan "AIDS is not a mainland disease."

In-service education has been provided for public health field staff, an AIDS information kit was prepared for all physicians, and information kits were distributed to representatives of major employers, unions, heath and allied health associations and the media.

AIDS education has been introduced into the school system, and teachers have received in-service education.

There have been many educational workshops provided for a variety of professional people and the general public.

Media

There are no universal guidelines for the media.

Any serious misrepresentation of information would be addressed by the Department of Health through a Press release. The media has been used extensively for public information campaigns.

Standardization of information

There is standardization of information through the Director of Community Health and the Provincial AIDS Public Education Working Group. The government is giving guidance on the private distribution of information, and literature has been produced.

Evaluation

The Province is pleased with what has been accomplished so far. An evaluation will be made this summer before any new programs are implemented.

Northwest Territories

Goals

The program will soon be hiring additional staff to provide more emphasis on AIDS counselling, professional education and training.

Public education is the major focus. It is hoped to hire an AIDS counsellor to answer the phone, to recruit volunteers, and also to do counsellor training as many of the nurses are uncomfortable with this subject matter.

There is a guideline for community education, and a Territorial Co-ordinator for AIDS. The only AIDS programs come out of this office and there is a tight control in this sense.

Personnel

AIDS education is primarily dealt with through:

- the Territorial Co-ordinator for AIDS.
- a full-time Public Affairs Officer.
- a full-time Researcher, who has been with the program for six months and is now moving over to the Medical Health Officer's office, and will be more involved in program evaluation.
- the AIDS Co-ordinating Committee, with representatives from the Department of Health, Education, Infectious Disease Control, NWT Nurses Association, Medical Association, and Medical Officer of Health. These act as an Advisory Group; they suggest and recommend rather than control programs. The general direction comes from them, but not day-to-day decisions.
- New positions to be filled:
    - counsellor/educator
    - nurse/educator

Community Leaders

It was believed that the first vital task was to reach the leaders. This has been a very important feature of the education program. The success of the program was put down to the fact that, in reaching the legislators and getting unanimous support from the Legislative Assembly, it was possible to establish strong support for educational programs before many cases of AIDS are diagnosed.

Voluntary and Community-based Groups

Volunteers are not yet a big part of the program.

Consideration is being given to training local on-site resource people to work within communities. This will not necessarily be through a nursing station, but will more likely be through a Friendship Centre on a drop-in basis. The funding for the next fiscal period provides for pilot projects and evaluation of these in communities.

Training

Six regional workshops brought together a nurse, teacher and community representative from each community in the area, including those with a population of only 250-400 people.

General AIDS information was reviewed, with special sessions for nurses regarding testing, and for teachers and community representatives regarding the AIDS curriculum for schools.

The focus will be on intensifying training in the small communities. This should begin in the Fall of 1988.

Media

The government has a very aggressive media campaign. On-going newspaper ads are changed every week, and special quarter-page and full-page ads have been used on occasion.

Ads are designed to reflect the special concerns of Northerners, targeting at various times the governmental population, the drinking crowd, bi-sexuals, and so on.

Ten television public service announcements using northern themes, people and scenes have been developed. Each spot is versioned in ten languages.

Standardization

Northern media have given the program a high profile, and usually check with the AIDS Co-ordinator before publishing information.

Central distribution of both NWT-produced pamphlets, and selected pamphlets and audio-visual materials from Southern sources, is done through the AIDS program and the Department of Health Resource Centre. Community educators are encouraged to use these materials rather than gathering their own.

An AIDS Update newsletter produced by the AIDS program is sent out bi-monthly to nursing stations, schools, social service offices, government offices, libraries, hamlet and band councils, and regional workshop participants across the Northwest Territories.

Revision and Evaluation

The regional workshops provided an important source for critiquing current programs and materials. These comments proved very valuable in bringing understanding of local needs.

A three-pamphlet package of standard information was applauded for the colours of pinks and purples. Other AIDS pamphlets in reds and blacks had been found to be frightening, and to remind people too strongly of death, terror and violence.

A poster had been produced showing one generic figure. The eyes were the main feature, the face was in shadow, and there was a message "Stopping AIDS is up to you." General feelings were that the figure was so obscure that it was difficult to know if it represented a child or an adult, and some people got confused, wondering if it was a child's disease. It also reinforced a feeling of secretiveness and isolation. The comments were taken seriously and the poster will be changed to a group of three people talking, with the new slogan, "Stopping AIDS is up to us, let's talk about it." The new poster shows Dene (Indian), Inuit and White people.

The program makes community input and involvement a priority. An effort has been made to adjust written materials to a Grade Four or Five reading level, and to provide translations into native languages.

Program Evaluation

The program's success has been attributed to the fact that the Legislative Assembly was involved from the very beginning, and clearly supported the program.

The educational program has been pro-active, stressing personal prevention as a means of stopping AIDS infection from reaching the northern communities.

Most evaluation was done through the regional workshops. The next phase will entail pilot projects with a large evaluation component built in. Community attitudes will be explored before and after training. The Northwest Territories has an excellent reporting mechanism for sexually transmitted diseases, and the rates will be monitored to help determine the efficacy of the AIDS educational program.

Nova Scotia

Goals

Priorities at this time are:

- to increase the public awareness of methods by which AIDS can be transmitted
- to prevent the spread of the AIDS virus
- to ensure that appropriate health care and other services are available to persons with AIDS and persons who are HIV positive and their loved ones, and that human rights are protected
- to provide a suitable co-ordinating mechanism for government policies and programs regarding all aspects of AIDS

Personnel

AIDS education is primarily organized through:

- Department of Health and Fitness District Health Units
- Department of Education
- One Family Planning Nurse in the Annapolis Valley
- MACAIDS
- N.S. PWA Coalition

Community Leaders

There is no specific program directed towards community leaders, although a major commitment was made in establishing the N.S. Task Force on AIDS to bring in a report to the provincial government. This is expected to be completed towards the end of September, 1988.

Volunteers and Community-based Groups

There are two community-based groups in Nova Scotia (MACAIDS and the N.S. PWA Coalition). These speak to interested groups and operate an information hotline, as well as providing resources and counselling support.

Training

Staff from district health units have spoken to community groups, service clubs, students, and employee groups, etc. on a request basis.

The Department of Education has provided in-services for teachers.

Programs

- In 1988 the Department of Health and Fitness distributed two brochures, "Information About AIDS" (included in power bills province-wide) and "AIDS and the Workplace" (made available to government employees and employers)
- TV and radio ads were produced and run by the provincial government in 1988
- Public forums and meetings were held by the N.S. Task Force on AIDS in major centres throughout the province
- Small-scale workshops have been held for the general public, mainly in conjunction with universities
- The Department of Health and Fitness produced an information kit for medical personnel (1985-1988) regarding guidelines for HIV infection
- AIDS education was introduced into the schools and made mandatory as of September 1988

Media

The media have run paid radio and TV ads, and produced a number of personal interviews on AIDS.

The N.S. Task Force on AIDS distributed CBC guidelines to the media, "AIDS: Reporting, Writing, Editing" (Guidelines for CBC Radio News March 1987, as modified by the Nova Scotia Task Force on AIDS, March 1988. Reprinted with permission of CBC Radio News).

Standardization of Information

Formal policies are not yet in place to supervise the standardization of AIDS information, but much of the information released to the public has been under the aegis of the Department of Health and Fitness.

There is no formal policy for the correction of misinformation.

Evaluation

The province is satisfied with the introduction of AIDS education into the schools. The provincial government is expected to announce future plans after the completion of the report by the Nova Scotia Task Force on AIDS in September, 1988.

Ontario

Goals

The major commitment of the AIDS program in Ontario has been in public education.

The underlying principle has been to fund community-based groups and to give them strong support in developing their own programs. The government encourages local initiative, and supplies staff and resources.

Personnel

There is an Advisory Committee on AIDS (OPEPA) and an AIDS Co-ordinator, as well as an Interdisciplinary Committee on AIDS.

Community Leaders

There has been strong government leadership in terms of deciding direction for AIDS programs (integration with existing services and development of local leadership) and the support of the Cabinet. There has recently been a training session for Liberal and NDP members of Parliament. The focus was on the pride with which so much has been accomplished. AIDS education materials and information packages were distributed to them.

Volunteers and Community-based Groups

There are ten community-based groups, all of whom are very active. The idea for the establishment of Casey House came from the public.

Training

There are strong training teams in the Speaker's Referral Service, the Public Health Units and community-based groups and volunteers. Public Health educators include nurses, clinicians, social workers, psychologists and clergy, among others.

Videos for the functionally illiterate are now being produced.

TV Ontario has been hired to provide teacher training through workshops and the production of materials.

Programs

- Ontario Public Education Panel on AIDS (OPEPA) was formed in October 1985, with the mandate to identify AIDS educational and informational needs
  - OPEPA and the Ministry of Health produced six fact sheets about the nature and transmission of AIDS for employees, parents, teachers, health care workers and groups most at risk. Fact sheets produced in seven languages (English, French, Portuguese, Chinese, Italian, Greek and Vietnamese); over four million copies were distributed.
  - established a successful speaker's referral service and developed three audio-visual presentations which are widely used across the province. The Speakers Referral Service has over 200 speakers, and they are matched to community needs as occasions arise.
  - December 1986, OPEPA's mandate was extended two more years. OPEPA was asked to continue its educational role as well as devise a framework for the development of the subsequently announced ministry-funded AIDS education and community support services.
- Provincial Advisory Committee on AIDS (PACA) was established July 1983
  - established a hotline at Toronto General Hospital for physicians seeking information.
  - set up a province-wide network of physicians to deal with referrals and local requests for information.
  - developed four information pamphlets on AIDS for use by physicians, dentists, hospitals, laboratories and funeral directors: Information for Physicians on HIV Antibody Test; Understanding AIDS and HIV; AIDS and HIV infection Psycho-Social Issues; AIDS Infection Control Procedures.
  - developed two videotapes: "AIDS After the Fear" (directed towards a lay audience) and "AIDS: A Challenge to Health Care Professionals."
  - developed an information package for physicians on HIV antibody testing, as well as a pamphlet for people who have tested positive for HIV antibodies.
- AIDS Committee of Toronto (ACT) received Department of Health funding for its counselling and support programs, and to develop educational materials.
- On November 27, 1987, 52 new AIDS programs were announced to provide AIDS information, education and support across the province.
  - funding for two years to Ontario health units to operate 37 local programs to provide AIDS education and information of the public, support local boards of education in implementing the mandatory AIDS school curriculum, and to carry out contact tracing of people infected with the HIV virus.

  - funding over two years to 16 community groups for counselling, education and support programs in cities with highest incidence of AIDS.

- Joint Ministry programs (Ministries of Health and Education)
  - TV Ontario is holding a series of workshops to train teachers and students about AIDS.
  - Workshops for parents and community groups are being held.
  - Ministry of Health, in conjunction with TV Ontario, is providing AIDS video programs to be distributed to schools and other non-profit organizations.
  - Ministries of Health and Education co-operated in preparing and circulating comprehensive guidelines for instruction on AIDS in Ontario's school system (September 1987).
  - Ministry of Health hosted the first Canadian AIDS Research Conference which included distinguished researchers and leading scientists from across North America (January 27, 1988).

- A Special AIDS section has been established within the Ministry of Health to
  - support Ontario's AIDS research efforts
  - co-ordinate ministry-funded AIDS education programs
  - monitor international development in the study of AIDS.

- On March 22, 1988, a massive two-year $7 million multi-media information program was announced (to begin immediately)
  - expanded English and new French Hotline
  - multi-language pamphlets
  - each Ontario home to receive a pamphlet
  - radio and TV commercials
  - province-wide transit cards (bus and subway)
  - new AIDS fact sheet in six languages
  - illuminated outdoor sign
  - outdoor transit shelter displays
  - use of newspaper personal columns for messages on the AIDS Hotline
  - public service announcements.

(Condensed from AIDS, FACT SHEET, March 22, 1988, Ontario Ministry of Health)

Municipalities have developed their own programs as well.

Media

There is a very vigorous mass media program. It has been recognized through monitoring the use of the Hotline that public interest and involvement increases or wanes according to the publicity given to AIDS, and that there is a need for consistent repetition of educational messages if complacency is to be avoided.

Standardization of information

OPEPA staff are available to the media to critique material that is being put on the air or published.

There is an on-going screening and testing of scripts for TV advertisements.

Misinformation can be brought to the attention of the Press Council as this is the regular channel to deal with complaints.

Evaluation

The Province is very satisfied with what it has accomplished with very few staff, a great many volunteers and heavy work loads.

A major factor in the success of the program has been the conscious application of a logical plan, and strong government support in implementing it.

It has also been well funded, and to date $19 million has been allocated towards public education, besides the money set aside for hospital costs.

Prince Edward Island

The Advisory Committee has almost completed its report. No major campaign will be considered until the decisions and recommendations of the Committee are made known.

There have been AIDS messages on radio and TV.

Preliminary goals have been discussed:

- there needs to be an integrative approach;
- the role of care providers has to be defined, in consultation with relevant groups;
- there needs to be accurate data techniques to monitor the spread of infection and plan for effective prevention of the disease.
- there is need to identify and counsel those who engage in high risk behaviour, to enable those who are uninfected to protect themselves, and those who are infected to avoid infecting others;
- to identify target groups and their professional and educational needs.

Quebec

Goals

Public education has been concentrated on public awareness campaigns, largely through the media. In the fall and at Christmas, much information was given out through the radio and TV, and this will be repeated in the Summer of 1988.

Last August, 1987, the major interest was in a program for looking at the issues surrounding the drug AZT, surveillance procedures and laboratories.

The next phase of programming will be launched after the Working Group on AIDS has made its report, and will probably be initiated in the fall of 1988. This Working Group on AIDS is expected to make its presentation to the Minister in August, and will include a study of ethical/legal/preventative/informational/educational and clinical issues.

Personnel

The planning for public education is largely in the hands of the Department of Health.

Volunteers and Community-based Groups

There are three active community groups.

Programs

The several public awareness campaigns through the media have been successful. Pamphlets, which gave very practical advice and information as well as the Hotline number, were produced and distributed.

Media

Both radio and TV have been used extensively for ads. Any misinformation would be corrected through the Department of Health.

Standardization of Information

Information and the production of pamphlets is in the control of the Department of Health.

Evaluation

The Province has been pleased with what has been undertaken so far. The report from the Working Group on AIDS will give a better idea of an evaluation, and what steps must be taken next.

Saskatchewan

Goals

The initial goal is to provide education and information about AIDS to the public.

The current goal is an integrated public education campaign. This includes both media coverage and a widespread Speakers Bureau.

Personnel

AIDS education is handled primarily through the Department of Health and through volunteer speakers. The Provincial AIDS Co-ordinator is also secretary of the Saskatchewan Advisory Committee on AIDS.

Community Leaders

Community leaders were consulted by the Minister of Health, through a symposium, prior to the development of the public education campaign.

Volunteers and Community-based Groups

The Speakers Bureau consists of 150 volunteers who have been trained to speak on AIDS, and they are a major feature of the AIDS education program. They discuss high risk behaviour, how the disease spreads, how to take precautions against infection, and they also give general information.

There are two community-based groups – AIDS Regina and AIDS Saskatoon.

Training

There are several programs to train community resource people. This is usually done through seminars.

The AIDS Co-ordinator assists in screening and training volunteers. Resource materials include an AIDS Information and Training Manual, videos and slides. Each trained community resource speaker receives a manual. The Community Health Regions co-ordinate local speaking engagements. An evaluation is completed on the effectiveness of the program and submitted to the Provincial AIDS co-ordinator for monitoring and for required changes.

Programs

A symposium was held in May, 1987, in order for the Minister of Health to consult with community representatives on AIDS. The proceedings have been published.

A media campaign was held in the Spring of 1988, including the use of radio, TV and newspaper ads encouraging a safer sex message. The initial phase was for six weeks, and a second phase is to be initiated in the fall of 1988.

- A provincial co-ordinator has been appointed to direct public education programming.

training individuals or groups.

- An AIDS Speakers Bureau was developed, through which more than 100 speakers throughout the province made themselves available to give public talks. The speaker's manual is in use in a number of occupational settings.
- A series of pamphlets has been produced for physicians, health-care workers, laboratory personnel, schools, day care, college and university students, and HIV-positive/AIDS individuals, and has also been distributed.
- Public information materials (film and video library, display materials, pamphlets, etc.) are being expanded.
- An AIDS curriculum has been developed for the schools but is not compulsory.

Standardization of information

The communications strategy comes within the provenance of the Department of Health, which has developed brochures, pamphlets, and TV and radio ads.

A major achievement was the production of an AIDS Training and Information Manual, to be used for the training of individuals and also for presentations about AIDS. In addition it is in use in a number of occupational settings, as well as in correctional institutions and young offenders facilities.

The AIDS co-ordinator is personally responsible for the editing of material, for making sure the message is clear, and for dealing with any public misinformation that comes to light.

Evaluation

Target testing was done before advertisements were released, to see how they would be received. This evaluation was positive.

The training manual is up-dated as required, and statistics are changed every two months.

The Province is satisfied at the progress which has been made.

Yukon

Goals

The most urgent aspect of the AIDS public education program has been establishing AIDS teaching in the schools. When British Columbia made AIDS education in the schools mandatory, the Yukon did the same, and this is recognized to have been a major step forward.

The focus of general public education is on infection control, personal values and lifestyle, and fears and prejudices.

The Yukon is a frontier area, and much of the population is transient, and so the challenge and needs are a little different from areas with a more settled population.

on AIDS, and to stress that AIDS exists as a reality. It will mainly be done by word-of-mouth, which has been found to be extremely effective.

Personnel

Responsibilities are shared between the Federal Health services, the Territorial Health services and Territorial Government Department of Education.

There is an Advisory Committee on AIDS which includes an Infection Control nurse, Medical Officer (also Director of Medicare) among others.

Community Leaders

There are two predominant groups. One consists of government employees and teachers, and so much of the education program has to be directed towards professionals.

The other predominant group is the native population. Numerically it is not large, less than 6,000, but it is significant in that it is hard to reach. The native community leaders and community health representatives (CHRs) who are working for the Bands are very valuable in taking the initiative to teach orally, largely by talking about AIDS in the course of every-day contacts.

Volunteers and Community-based Groups

There is not a very active volunteer group, except in Home Care and the Hospice Association. They are struggling to become established.

Training

The Communicable Disease Officer in Whitehorse is the resource person for training groups. She collaborated in writing a manual on AIDS for the Federal Government, for Medical Services Branch. It is in use in all federal government nursing stations, and has been distributed throughout Canada.

Programs

There is soon going to be a household drop of general information on AIDS emanating from the office of the Minister of Health, Government of Yukon Territory.

Media

There is no local advertising on TV, but Northwest Territories AIDS commercials appear regularly. Radio has been used extensively for providing AIDS information. There have been "phone-in" programs, and a "walk" through the STD clinic with a person being tested for AIDS.

Standardization of information

Pamphlets are purchased, or produced locally. Some are original, and others have incorporated ideas from a number of sources, or are duplicated.

Factual material for programs comes from the office of the Communicable Disease Officer, and tion.

Evaluation

The Territory is pleased with what has been accomplished in the schools, and is now concentrating on information programs for the general public.

Summary

National/Federal

The National Advisory Committee on AIDS (NAC-AIDS) acts in an advisory capacity to the Ministry of Health and Welfare, and makes recommendations on AIDS issues.

The Federal Centre for AIDS (FCA) plans, directs and co-ordinates federal government AIDS activities under the National AIDS program, and as part of the Health Protection Branch of Health and Welfare Canada.

The Federal/Provincial/Territorial Advisory Committee on AIDS provides the means of planning and co-ordinating the activities of both levels of government.

The Canadian Public Health Association (CPHA) is mounting a Canada-wide public education and awareness program over five years, starting 1986. The work of this non-government association complements that done by the Federal Centre for AIDS.

In May 1986, a $39 million five-year national program for AIDS issues was announced by the Ministry of Health and Welfare. This program is directed towards a number of AIDS issues, including research; public education and awareness programs; conferences; national and international liaison efforts; dissemination of information on AIDS; the production of materials on AIDS; establishment of resource centres; development of media programs; and the training of personnel.

Provincial

Department of Education:

- Incorporated AIDS education into the schools curriculum: New Brunswick, Newfoundland, Prince Edward Island (using Ontario materials while developing curriculum), Ontario, Alberta, Manitoba, Saskatchewan, Northwest Territories, Yukon, British Columbia, Nova Scotia.
- Curriculum entirely the responsibility of school boards: Quebec.
- AIDS Education Council established by Minister of Education: Manitoba.

Department of Health:

- AIDS Committees established: in all provinces and territories.

- Public Education Campaigns: in all provinces and territories

National

The possibility of funding a national Hotline is being discussed at the Federal level.

If one is established, it will be linked to existing provincial lines.

Alberta

The STD* Education Unit maintains an information line for sexually transmitted diseases, including AIDS.

A province-wide toll-free AIDS Hotline is provided under Alberta's three year plan. It is staffed by Nurse-Educators who are "knowledgeable about HIV infection ad other sexually transmitted diseases", and it will provide information for the general public. After regular working hours, disease information and referrals are provided by a recording.

British Columbia

There is a toll-free government Hotline in Vancouver. It has four different lines, one of which is long-distance. It was established through the office of the Director of STD Control and is maintained under his budget.

The service was designed to give information about AIDS rather than counselling, but counselling is provided if it is needed.

Only English is spoken.

There is a special device for the hearing impaired.

Two other Hotlines are provided by AIDS Vancouver and AIDS Vancouver Island.

During the first four weeks that the government Hotline was in operation approximately two thousand calls per week were received. At this time, (May 1988), there are about six hundred calls per week. Of these, about two hundred come through during the working day. In the evenings and at weekends a tape is put on, and about four hundred calls are usually received during these hours.

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* Sexually Transmitted Diseases

Manitoba

The Manitoba Health Department has established an AIDS Information line which provides information and also refers callers to other sources of help if in-depth counselling is needed. Information includes recommended resource material, and details of support groups for people who are infected with the AIDS virus and their families.

The Village Clinic also has an AIDS information line and focuses on counselling.

The government is working with the Immigrant Centre to reach immigrant leaders, and translations are being made into other languages.

At the peak of the media campaign, the Hotline received an average of sixty calls a day.

New Brunswick

Forty-three volunteers, two evenings a week, man the toll-free Hotline to give out information, answer questions, and refer people who are HIV sero-positive to continuing support and emotional help if they need it.

Volunteers get twelve hours of training, conducted by community resource people. They are also provided with a resource book from San Francisco.

Training is focussed on five areas: medical and epidemiological aspects of AIDS; human sexuality; crisis and telephone counselling; role plays of likely scenarios; housekeeping – filling in log sheets; responsibilities; rights; telephone etiquette.

The number of calls between 7:30 - 10:30 pm varies between 0 - 6. During daytime hours the AIDS New Brunswick office receives 4 - 5 Hotline calls from people who have called when the recorded information has been played and then contacted the office the next day at their own expense.

The types of calls in order of frequency are:

- Concerning transmission of infection (from fears about casual contact to fears about high risk behaviour)
- Risk assessment (anxiety about having "done it once" to sexual involvement with many partners)
- Testing (following risk assessment, people generally want test information)
- Safer sex (particulars)

- Support (calls come in immediately following diagnosis, both from people who are infected with the HIV virus, and their family and friends)

Volunteers are carefully screened during their training period. If they are uncomfortable and cannot respond readily at every caller's level, they are not allowed to be a volunteer. Some of the people calling in use street language, and many are also only prepared to spend an extremely short time on a call. A volunteer must often respond very quickly and to the point. This is a highly important consideration as a good proportion of the people who call in are thought to engage in high risk activity and also difficult to reach. Child Find believes that there are about two hundred adolescent prostitutes, some of whom are probably functionally illiterate, and for that reason alone more out of touch with the usual channels of communication.

A very important function of the Hotline is that it is the only means by which a person can be assured of anonymity if they ask for AIDS counselling. Callers are strongly encouraged not to identify themselves. It has been thought that a number of heterosexuals and bi-sexuals, sectors of the community who are usually difficult to reach, have had the confidence to use the service because of this policy if anonymity.

Newfoundland

There is no Hotline, but the establishment of one is being considered by the Newfoundland Labrador AIDS Committee.

Northwest Territories

Calls currently go through the office of the AIDS Co-ordinator. So far there are about ten a week.

The Hotline number will initially be advertised with the introduction of the television public service announcements at the end of June. The new counsellor/educator will have primary responsibility for handling calls.

Initially calls will be answered only in English, but a sophisticated telephone answering machine has the capability for playing informational messages in Native languages on the open line.

In the future Native people will be recruited and trained to handle Hotline calls.

Literacy is not a problem as numerals are well read.

Nova Scotia

There is no provincial government Hotline in Nova Scotia. The Department of Health and Fitness has the ability to respond to calls through its regional offices, but this service has not been advertised specifically in regard to AIDS.

The Metro Area Committee on AIDS (MACAIDS) has a Hotline which is open during business hours. It is not toll free. Information is given out about AIDS, and referrals are made for counselling if this is required. There is a part time counsellor in the MACAIDS office.

Ontario

The Province has a toll-free Hotline in French and English, and there is one in Toronto and another in Ottawa (which is francophone).

The Hotline provides information, counselling and referrals to community-based groups.

A special device for the deaf has just been initiated, and an enquiry has been made on behalf of the blind through the Canadian Institute for the Blind, but this is still being discussed.

The provincial hotline is funded and maintained through the Ministry of Health.

The number of calls is closely related to advertising. When there is a major advertising campaign, the lines are swamped, but calls die down in between these efforts. This has underlined the need for constant and continuing advertising promotion.

Prince Edward Island

There is no Hotline yet.

The AIDS Advisory Committee will be reporting back in a few weeks about the advisibility of introducing one.

Quebec

There is a twenty-four hour Hotline for the Province. Special teams answer questions, and give information and a little counselling, in either English or French.

Saskatchewan

AIDS Regina and AIDS Saskatoon both operate Hotlines. In addition they both have a six minute recorded information program.

Also AIDS Saskatoon has a buddy system counselling line. There is a PWA Coalition Support Group that callers are referred to. In the seven months that the Hotline has been operating, Regina has had 1,137 calls, or 162 calls per month (August 1987 - March 1988). Forty-three percent of the calls were from women, 57% from men.

Yukon

A Hotline has not yet been established in the Yukon, but plans are being made to use the British Columbian Hotline.

Calls currently go through the office of the Communicable Disease officer in Whitehorse General Hospital. There have been approximately a dozen calls to date. (May 1988)

Summary

Information given about Hotlines was as follows:

Established Hotlines

NB	-	Dept of Health in conjunction with AIDS New Brunswick
Nfld	-	The Gay Association private line. (Gov't discussing establishing hotline)
PEI	-	None. (AIDS Advisory Committee discussing the issue)

Quebec	- Dept. of Health 24-hour line
Ontario	- Dept. of Health line
Alberta	- Dept of Health line - STD Info Line
Manitoba	- Dept. of Health Information line - Village Clinic Information line
Nova Scotia	- no dedicated line. Dept. of Health and Fitness regional offices respond to enquiries - MACAIDS line
Saskatchewan	- No government line - AIDS Regina information line - AIDS Saskatoon counselling line
Yukon	- None. Calls go through Dept. of Health office. (Discussing utilizing BC line).
NWT	- Calls go through AIDS Co-ordinator now, and after June 1988 they will go through the newly appointed counsellor-educator. (Information line in planning stages, utilizing sophisticated answering machine to handle ten languages).
BC	- Dept. of Health line - AIDS Vancouver line - AIDS Vancouver Island line

Special mention was made that consideration be give to the following points when introducing a Hotline: Volunteer training program, Provision for the deaf, provision for the blind, Provision for immigrants, Provision for more than two languages.

Targeted Education

Federal

"The AIDS crisis requires that we be men and women of vision. Will we in ten year's time be able to satisfy ourselves that we did all we could?"

(Minister Jake Epp, at the World Summit of Ministers of Health, Jan. 28th, 1988)

Alberta

Identified:

- Homosexual activity
- Intravenous drug use
- Mothers and babies at high risk
- People who may experience accidental exposure in the workplace (or who are more at risk than average because of their kind of work). As well as health care workers, these include personal service workers, such as embalmers, electrolysists, and tattoo artists.

Outreach:

A three-year program has planned for:

- A special mass media campaign targeted at high risk behaviours, using TV, radio, billboard, newspaper and bus advertising. Messages will stress the vulnerability for acquiring infection; that testing is available for those that wish to use the services provided; and that educational programs and support are being offered in the community.
- Risk reduction programs which change behaviour and reduce the risk of acquiring or transmitting HIV infection. These include one-on-one counselling by physicians, STD clinic staff, and the staff of the AIDS Networks in Edmonton and Calgary, and peer group counselling by the AIDS Networks. Educational messages emphasizing specific behaviours with recommended alternatives are being targeted to those with high risk behaviour, largely through leaflets and brochures, presentations at gay clubs, etc.
- An inter-agency group is developing a proposal for a pilot outreach program to reach street drug users in Edmonton.

Funded Community agencies will do much of the work.

British Columbia

Identified:

- Homosexuals
- Bi-sexuals (and their heterosexual partners)
- Intravenous Drug Users
- Prostitutes and Drug Users
- Runaways and Teenagers on the Street
- Native Indians
- Prison Inmates

Outreach:

- There are extensive on-going education programs. As well as these:
- A "Nurses on the Street" program started in January, 1988. It includes testing, counselling, education, making of referrals, handing out bleach bottles and condoms with information on how to use them.
- A pilot AIDS education program for Native Indians is being tried out by one of the Bands.
- A preliminary program which includes testing and giving information about AIDS has been initiated in some prisons.

Manitoba

Identified:

Risky Activities:

- Sexual
  - More than one partner
  - anonymous partner
- Drug users
  - needle sharing

Outreach:

- Provincial and federal government have jointly funded the Village Clinic which deals primarily with persons who are or maybe infected with HIV. The Village Clinic in turn has outreach programs with "street people", drug users, and persons in the sex trade industry.
- Public Health nurses involved in the STD Control program also deal with similar populations and provide education and counselling. One on one contact is often essential.

- Communicable Disease Control is working with the Village Clinic, Alcoholism Foundation of Manitoba and detoxification treatment centres to develop programs to deal with drug users.
- The various gay groups and the Village Clinic have provided educational programs aimed at risk reduction to the gay community.

New Brunswick

Identified:

- Homosexuals
- A very small group of IV drug users, (recognised to be difficult to reach).
- All prostitutes, but with a special focus on fifteen to eighteen year olds, mostly (though not exclusively) males serving bi-sexual males.

Outreach:

- Ten students have been hired for the summer to work in five different communities. They will be giving out basic information and answering questions, trying to meet with as many of the public as possible.
- Child Find has a grant to train street workers.
- Guidelines have been developed to provide standardized information on awareness and education programs for groups associated with high risk behaviours.

Newfoundland

Identified:

- Homosexuals

* It was noted that IV drug use is not known to be a problem with respect to AIDS at this time.

Outreach:

- The Department of Health has had discussions with a community group consisting of gay men and "concerned others" who wish to develop a program similar to MACAIDS (in Halifax, N.S.). It will be health oriented, and include one-to-one and peer counselling. Plans for its development are still evolving.
- Materials are developed with the functionally illiterate in mind.

Northwest Territories

Identified:

- Men who have had sex with other men
- Men who have had sex with both men and women
- People who share needles to inject drugs
- People who have had large transfusions of blood or blood products between 1987-1985
- Anyone who has had sex with someone in the above groups
- A strong association between alcohol abuse and high-risk sexual activities is also emphasized.

Outreach:

- The AIDS program is just beginning to prepare AIDS education messages directed towards homosexuals.
- A strong correlation has been perceived between alcohol abuse, clouded judgement and unsafe sexual behaviour. It is hoped to get community groups involved in helping to deal with this.
- The program recognizes and articulates that it is sexual behaviours which constitute risk, not the perceived social grouping.

Nova Scotia

Identified:

- Homosexual activities
- * It was noted that IV drug use is not known to be a problem with respect to AIDS at this time.

Outreach:

- The Department of Health and Fitness has financed MACAIDS to employ an AIDS Education Co-ordinator to work with the Gay community.

Ontario

Identified:

- Homosexuals
- Bi-sexuals
- Intravenous drug users
- Prostitutes
- Street kids
- Haemophiliacs
- Minority cultures
- People with language differences
- The illiterate

Outreach:

There is a strongly developed policy for the government to facilitate help but not to impose it. Local groups and communities are encouraged to develop their own programs, and to apply for funding in order to do so.

- Outreach is in the form of a funding mechanism through appropriate groups. For example:
- A group has come forward with a proposal to promote safer sex.
- Another group is concerned with the rights of prostitutes working in the streets and out of doors.
- Four Indian Bands are developing education programs for their own people.
- Focus has changed from talking about "at risk groups" to discussing "risk activity" and personal responsibility for protecting oneself. (A focus on "groups" makes it much easier to deny personal involvement.)

Prince Edward Island

The risk of contracting AIDS in Prince Edward Island at this time was thought to be very low.

There is not an active gay community, and there are very few people who are known to be intravenous drug users.

The heavy tourist trade might pose some threat, but this is only speculation.

The situation is not at all tangible, and it is difficult to decide what measures should be taken. There has been one case of AIDS to date, although there is a second one developing.

The Task Force on AIDS is expected to bring in its report in early summer.

Quebec

Identified:

- Haemophiliacs
- Haitians

Outreach:

- The Minister of Health is expected to announce a new plan of action for this fall.

Saskatchewan

Identified:

- Homosexuals

Outreach:

One focus of AIDS Regina and AIDS Saskatoon is to deliver programs specifically targeted to the homosexual community. Government programming places emphasis on both general population needs and the information needs of groups associated with risky behaviours.

Yukon

Identified:

- Native population
- The Institutionalized
- Women

Outreach:

- There is a small Native population, less than 6,000 people, but some of them have lived in the big cities to the South and then returned home to the Yukon. They are quite difficult to reach. A few of them come for testing and recognize the risks associated with AIDS. All of them speak English.

An attempt is being made to approach them through the Native Community Health Workers who act as assistants to the Public Health nurses and work with the Bands. They have been asked to suggest by word of mouth that it might be a good thing to have a blood test, and it has been seen that changes are very slowly taking place.

- The Health authorities have close contact with the Institutionalized.
- About 40 persons are seen in the STD Clinic in a four-week period, and so they have become a natural focus for one-to-one AIDS education and counselling.

A special note was made of the fact that the Yukon is a frontier area that has a population from all parts of the world. Many seek testing and make a point of arranging for it, and there is not such a pressing need to identify target groups as there might be in some areas.

There are Homosexual and Lesbian groups in the Yukon, but they are not distinct from the rest of the public. Some are transient in that they work in the Yukon for awhile and then usually move away again.

Summary

The Provinces and Territories identified groups which are currently targeted as being difficult to reach through the general public education and awareness programs, and which may require extra effort and creativity to communicate with. The use of the word "group" here is in no way intended in a pejorative sense, but to convey reference to activities which, for brevity's sake, have often been "grouped" even though this may appear unjust to individuals. "Groups" which were specially identified within provinces as participating in high risk behaviour and to whom education programs are presently being directed were:

Homosexuals
- NB, Nfld, Ontario, Alberta, Saskatchewan, Manitoba, NWT, BC

IV Drug Users
- NB, Ontario, Alberta, Manitoba, BC, NWT

Prostitutes
- NB, Ontario, BC

Haitians
- Quebec

People having more than one partner
- Manitoba

People having an anonymous partner
- Manitoba

Bi-sexuals
- Ontario, NB, BC, NWT

Heterosexual partners of bi-sexuals
- BC

Functionally Illiterate
- Newfoundland, Ontario

Street Kids
- Ontario, Manitoba, Saskatchewan, BC

Tattoo Artists
- Alberta

Electrolysists
- Alberta

Mothers/Babies
- Alberta

Native Peoples
- Manitoba, Saskatchewan, Yukon, BC

Minority Cultures
- Ontario

People with Language Differences (not English)
- Ontario

Sexually active young adults
- Manitoba, BC

The Institutionalized
- Manitoba, Yukon

Prison Inmates
- BC

Women
- Yukon

Alcohol Abusers
- NWT

Accident cases in the Workplace
- Alberta

Embalmers
- Alberta

People who have had large transfusions of Blood
- NWT

Haemophiliacs
- Ontario, Quebec

Sexual contacts of people maintaining high risk behaviour patterns

- NWT

Health Care Workers

- Alberta

To reach targeted groups associated with high risk behaviour, a number of varied approaches were adopted among provinces. These include: Hiring of student counsellors, Training and hiring of street workers, Standardizing information for education programs, Development of materials, low reading comprehension, Programs for gay men, Encouragement of community groups, Programs for Native Indians, Media campaign for high risk groups, Counselling (including peer and buddy), Programs for prison inmates, Programs for the Institutionalized, Programs for street kids, young sexually active adults, AIDS education for alcohol abusers.

Schools

Overview

"What Must School Boards Do?

Assisting in the prevention of the spread of the disease

> While numerous non-medical proposals designed to curb the spread of HIV have been advanced from time to time, the only one which has met with well nigh universal expert approval is the education of all sectors of society:
>
> > *Education . . . is said to be the best and most effective response – far more likely to contain the spread of the [HIV] virus . . . than [reliance] on the dimly perceived risk of criminal punishment or civil action. These are, after all, infinitely less frightening, contemplated in potential than the acquisition of the terminal condition itself. (Kirby, 1986)*
>
> School boards can play a critical role in the containment of HIV by helping to change common behaviors that are likely to spread the virus:
>
> *Educating employees*. It should not be assumed that employees necessarily are aware of all the facts or the social, ethical, and legal issues raised by AIDS – witness the reaction of the Nova Scotia Teachers' Union.
>
> *Educating students*. Students need accurate, explicit, comprehensive information about AIDS – its cause, its effects, its prevention. This is particularly true of high school students . . . . who will become the most sexually active members of society and therefore be most at risk of acquiring the virus and, if they do so, of transmitting it. Indeed schools provide an opportunity that must not be passed up; to reach future members of society, some of whom, once they leave school, will become unreachable. Information concerning AIDS should be included in all health, drug, or sex education courses offered by the school. If there is uncertainty about how the subject can be incorporated in a course, about the facts on the subject, about the appropriate level of specificity with which pertinent matters should be treated or how to handle student reactions, expert assistance should be sought from those who already have had to deal with this issue.
>
> *Educating the community*. To a degree, this will be achieved indirectly through the dissemination of the information received by staff and students. However, school boards should extend their education into the community with the co-operation and assistance of knowledgeable members of local health and social service agencies. . . .
>
> . . . [C]are will have to be taken that the educational programs provide not only as complete and accurate a picture as possible but also convey the information and treat the unknowns and uncertainties in an objective, unbiased, and responsible manner. The roles and attitudes of those providing education about AIDS are extremely important in dealing effectively with the many and varied issues raised by the disease. It is not enough that instructors merely convey the facts – they will also have to explore their audiences' fears, attitudes, values, beliefs, and knowledge. This may provoke some parental and community opposition, for it may be seen as constituting an unwarranted invasion of privacy, an encroachment on the free exercise of religion, or the promoting of unacceptable mores, sexual promiscuity, or 'deviant' lifestyles. However, such broad educational initiatives are justifiable on the basis of the community's concern about, and interest in, protecting the health and welfare of students. . . . [N]ot to educate students about such matters as sex, drugs, and AIDS is to do them and the broader

community a great disservice and to invite even more serious societal problems than currently exist." One goal of education is "to expose students to facts and a range of options that are appropriate to the age and sophistication of the students, so that they are in a position to make informed and responsible choices. It is contrary to the notion of responsible education as a market place of information and ideas.

Accordingly, broad educational initiatives at the school level are essential to combating both the spread of HIV and the hysteria, fear, and prejudice which are generated in some people by AIDS.

Such initiatives, moreover, are essential in creating a more accepting climate for persons who have been infected with HIV or are suffering from AIDS – which is the second major challenge that confronts school boards."

(From *The Canadian School Executive*, October 1987. Article by Dr. William F. Foster, McGill Centre for Medicine, Ethics and Law.)

The Health Information Network

Principles of Education and Behavioral Change

To be effective, education to end the spread of AIDS and other diseases needs to change the health-related behaviors that put people at risk. But behavioral change will not result from the simple process of providing information. Successfully persuading individuals to alter their behavior requires more complex strategies – strategies based on specific, research-based principles. The Senior Science Advisory Group, a panel of distinguished scientists within the Health Information Network, cites 9 principles that have the potential to link education to behavioral change.

1. Effective health education rests on both a *scientific and an ethical* foundation. No value is more fundamental than the sanctity of human life.

2. What constitutes healthy or risky behavior can be objectively established by scientific investigation. But the decision to practice or to reject healthy behavior always remains a personal moral choice.

3. Health education that relies only on the transmission of information is ineffective. Behavioral change results only when information is supported by shared community values that are powerfully conveyed.

4. Health-promotion programs must go beyond one-shot approaches. Effective programs are persistent, persuasive, and sustained.

5. Effective health education derives from many important sources: family, school, peer groups, the neighborhood, religious organizations, the workplace, the commercial media, and the unique leadership within each community.

6. Schools and communities that work together to promote health and combat health problems *will develop their own individual programs* – programs that respect *both* the scientific (that is, replicable) facts about health-enhancing behavior *and* the texture of values, traditions, and ethical convictions within those communities.

7. Our attitudes toward new information, and the reasons we use or refuse to use that information (e.g., the scientific finding that cigarette smoking endangers health), are the same for children and adults. Both children and adults who "know better" nonetheless persist in health-debilitating patterns of behavior.

8. Efforts to deter unhealthy sex-related behavior rest on the same principles used in attempts to deter reckless or drunken driving, cigarette smoking, drug abuse, unhealthy nutritional habits, and obesity.

9. Everyone needs the opportunity to practice the skills necessary to change the behavior of family members, peers, friends, and fellow workers. Among teachers, mutual support and peer consultation will be essential. Community support is necessary to support and legitimate the health education efforts of teachers.

From "NEA Today" (The National Education Association) Sept. 1987 issue.

Federal

National Consultation with Education Community

A two phase project has been commenced to provide an opportunity for national education organizations, provincial and territorial ministries of education and the federal government to develop a comprehensive strategy for AIDS education of in-school children and adolescents.

This strategy will identify the most appropriate role for the federal government, alone or in concert with others, in the development of AIDS education materials and programs for Canadian youth.

(From Federal Centre for AIDS: Communications and Education Services Education Programming Update - Jan. to May 1988).

Alberta

AIDS Education

AIDS education has been incorporated into the junior high school health curriculum for grades seven to nine. It is included in the Sexually Transmitted Diseases education course as one segment of an optional eight-to-nine-hour presentation on human sexuality. It is at each school board's discretion whether or not this course will be given at any particular school.

A revised curriculum for senior high schools has been pilot tested in 1987-88 and will be implemented in the schools in 1988-89. It is hoped that school boards will be enthusiastic about accepting this, and help to promote it.

It was noted that one of challenges to educators will be to bring out into the open the differing values systems and thinking on morality, while at the same time maintaining a level of tolerance. Part of Alberta's educational strategies will be to wrestle with how to present this in the schools in an attempt to change the behavior of those engaging in high risk activities, without offending those whose values prohibit such conduct, and may be upset with educational messages dealing with risk behaviours. ("Education and Caring: Alberta's Program for AIDS". October 1987, Obj.1.3)

Training and Involvement with the Health Department

Seminars are provided for teachers through the STD* Education Division. Based on these pilot seminars, it is intended to organize further seminars in continued co-operation with the Department of Alberta Education. This is part of Alberta's three-year AIDS education program which began in 1987.

STD Education Unit staff address children in junior and senior high schools by invitation. There were 427 sessions in 1986-87, involving approximately 2,800 students. STD staff also assisted with the provincial in-service for teachers when the new curriculum was launched.

Part of the role of health personnel has been to encourage and support the sexuality component in the junior high curriculum, (since it is taught at the option of the school board).

Resource Materials

The Departments of Education and Community and Occupational Health have together identified authorized resource materials for students and teachers, and the government has subsidized audio visual and print resource materials for the new AIDS program through the three-year plan funding.

Guidelines

A joint statement from the Alberta Community and Occupational Health and the Alberta Education Department contains guidelines on AIDS in educational settings.

Children with AIDS

The information bulletin on the education of children with AIDS or HIV infection has been up-dated and re-issued.

British Columbia

AIDS Education

The Ministry of Education, in collaboration with the Ministry of Health, completely revised the school curriculum to include a major emphasis on AIDS and sexually transmitted diseases. This was introduced into the schools in September 1987. ($4 million dollars was granted for this project).

The AIDS curriculum is mandatory, and begins at grade seven.

Grades seven to ten get twelve hours of instruction, and this is presented through six two-hour modules.

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* Sexually Transmitted Diseases

Grades eleven and twelve have four hour-long modules (or each student gets a module every year).

Topics include friendships and relationships, reproductive biology, AIDS and other sexually transmitted diseases, and decision-making and assertive communication.

School boards have a wide choice of what they will include in the program, from the provincially-produced teaching materials to a range of options

Information about preventive measures, like the use of condoms, is given in a very factual way, with no religious or moral stance. Students are educated in how to make responsible decisions.

Training

An effort is made to see that the AIDS curriculum is taught by teachers who have a genuine interest in it. Some schools hired special teachers.

Teachers were also give training in special workshops last summer (1987). This was mandatory for public school teachers.

Teaching Resources

A curriculum guide, featuring lesson plans and teaching materials, is provided with the program. It includes background information for teachers, and student handouts. There are suggested videos, instructions for workshops, and for question and answer periods.

A video was produced especially for grade twelve students, and was distributed to every secondary school, college, university, and public library, and to over 500 video stores.

Parents

A Family Life Education curriculum was also produced for parents so that they could teach their children about AIDS in their own homes. This has been used very little. Since AIDS is mandatory in the schools, most parents do not bother to duplicate this formally at home.

The launching of the new schools program coincided with a massive public education program, which included the delivery of a pamphlet, "Talking With Your Children About AIDS - A Parent's Guide" to every family in British Columbia.

Manitoba

AIDS Education

"Manitoba Education has developed a curriculum on AIDS for incorporation in the core curriculum in grades 7-9, plus a stand-alone curriculum for high school. The curriculum is open to adaption by school divisions and features a three-to-four hour instruction package that, in grades 7-9, is part of the community health unit of the health education program. The focus is on the cause, nature and prevention of the disease, with lessons on the effects of AIDS on the immune system. In the senior grades, the package can be presented as part of biology or other courses, or in a special student assembly. Here the emphasis is on what AIDS is, how it is transmitted, and how it can be prevented." (Excerpt from document prepared by Canadian School Trustee's Association)

The draft curriculum was circulated to divisions for feedback (in October 1987) and revisions were subsequently completed. The final curriculum was introduced into the schools as of February 1988, and is compulsory for all students.

In the junior high curriculum (7, 8, 9), auxiliary lessons on the immune system, peer pressure and relationships and the media are offered if the advisory committee agrees.

Although it is a compulsory programme, there is also an opt-out clause through which parents may withhold their children from AIDS education.

The high school program is a "stand-alone" unit. It is mandatory, and provides three to four hours of information followed by a number of auxiliary exercises. (Extra materials and strategies can be used at the school's discretion.) The course could be presented on one afternoon or a day's session. Some schools have used experts who have given major presentations, and others have had small-group workshops. The format is up to the school, and there is room for flexibility.

The materials were adapted for Manitoba from an Ontario program. Some guidance is given in the use of condoms. Whether or not there is a religious or moral stance varies with each school. The material in general is informative. Abstinence is promoted.

Government Funding and Provision of In-Services

Funding for the new program and province-wide in-servicing was provided through the Curriculum Development and Implementation Branch of Manitoba Education. Manitoba Health and Manitoba Education jointly planned the in-service program. A representative from both departments formed the in-services resource team.

Guidelines

Manitoba Education has developed implementation guidelines, and the first draft went to the school divisions in October.

Parents

An information booklet for parents has also been produced. There are no specific programs for parents except through the general media and school divisions. They are encouraged to review their children's work.

Media Presentation

Representatives from the Manitoba Health and the Curriculum Development and Implementation Branch have appeared on the Peter Warren Line.

New Brunswick

AIDS Education

The Department of Education has developed curricula for the Anglophone and the Francophone school systems. Initial steps included the development of policy guidelines for Department of Education staff. This was released in 1987 and received considerable public debate.

The Anglophone curriculum has been piloted in a number of areas already and has been well received.

AIDS education programs are being designed to be delivered as early as grade seven. The greatest emphasis is on students in the upper grades.

Department of Health Involvement

The curriculum was developed by the Department of Education with the assistance of the Department of Health and Community Services professionals. Public Health staff have given training to teachers through formal seminars and in-services.

Training and In-services

Teachers delivering the pilot programs have received in-service training.

Parents

Parents have the choice of keeping their child out of class if they wish.

Newfoundland

AIDS Education

AIDS education begins in the recommended program at Grade 9, but school districts also have the option of dealing with it in Family Life, Family Studies, and/or it can be aligned with any suitable course (as, for example, religion, biology, science, family life). In fact this approach is endorsed and encouraged by the Education Department, and it is hoped that teachers will include AIDS education wherever it is relevant, if the subject comes up for discussion. The Department will provide necessary materials as the need arises. It has also made suggestions as to how AIDS might be included in many different classroom situations, including the lower grades. There is a graduated information approach.

Policy Guidelines

The Department of Education has provided Policy Guidelines to school districts to help them in developing their own policies on AIDS and AIDS education, and given an information leaflet to all teachers and whoever else is involved. The School Boards and Parent/Teachers Association work within these guidelines to develop statements. Although they develop their own policies, each school board used the expertise of the local Public Health person or Medical Officer of Health in working towards this.

Schools are Denominational

All schools are denominational in Newfoundland, and everything is taught against the backdrop of the denominational system. A certain religious stance may be presented, and it is incumbent on the teacher to address denominational concerns. AIDS teaching is not part of a personal relations and growth program as such, but it has that aspect. Some boards have developed their own programs for AIDS education.

Grade Nine Course

The proposed compulsory Grade 9 course is entitled, "Adolescence: Relationships and Sexuality". These materials include a resource book for teachers and a student booklet. Teachers have to attend a compulsory two-day in-service. AIDS is incorporated with the STD material. If they wish to, teachers can ask for supplementary materials, and are offered two complementary booklets and a video:

"AIDS: What Every Responsible Canadian Should Know" (Teacher's resource book)

"AIDS: What Every Young Adult Should Know" (Teacher/student booklet of detailed information related to prevention of AIDS)

VIDEO: "AIDS, What Everybody Should Know".

The adolescent program includes background information for teachers on the use of condoms.

There is an Education Consultant for Home Economics and Family Studies working with the Grade 9 program. She also evaluates the in-services, and has found the response to be very positive.

Materials for the Department of Education

The Department of Education is involved with previewing and reviewing videos and printed materials on an on-going basis. It purchases materials and also makes recommendations. Only the ones it endorses are listed for use in the schools, (although schools are free to buy other materials if they want to). "This is a monumental task".

In-service Training and Informative Talks

A Physical Education and Health Consultant has been doing numerous: in-services for teachers and school boards. (She has done 35 in-services this year).

She is geared to taking teachers through the process of teaching rather than to give them information. The package she uses is developed in the following way:

1. Overheads to define what AIDS is

2. Discussion of the three stages of infection; HIV, ARC, AIDS
3. Transmission of the disease
4. How AIDS is NOT transmitted
5. Education on avoidance, prevention, at-risk behaviour
6. Making responsible choices
7. AIDS in school:
    - personal hygiene
    - precautions in handling body fluids
    - empathy for AIDS patients
    - Department of Education policies and resources that are available, i.e.: people/courses/videos/printed matter/materials.

She also provides information at all levels of schooling. In the STD Course, the first thing that is talked about is AIDS, as the students are most interested in that, and find it hard to listen until that is discussed.

Both the Education Consultant and the Health Consultant have responded to enquiries through the media, in both radio and TV interviews, giving details of what the Department of Education is doing about AIDS education, and answering questions raised by the public, as well as attempting to alleviate fears about the disease.

Department of Health Involvement

The Department of Education works very closely with the Department of Health, and both co-operate in the development of materials and handling of information. It is suggested that Public Health nurses should be involved in all meetings about AIDS education and in-services. The Department of Health has developed lesson plans for use by the public health nurses and the schools. There are two for use in the junior high program, and two in the high school program. Additional lesson plans are being developed for use in the primary grades.

Parents

It is part of the responsibility of schools to make parents aware of the contents and goals of the Family Life Program, to provide them with information and to answer questions. The Department of Education encourages dialogue between parents and teachers; practice tends to vary with the school district.

There is also a parent's meeting in the Adolescence course. Apart from this, there is nothing formal in the school system for parents. The Physical Education and Health Consultant has filled an important gap in this respect, and has had meetings with parents in a number of communities.

The Parents/Teachers Association has also asked for guest speakers.

Alternative Education for Children with AIDS

Alternate education for children with AIDS would come under the same system as that provided for children with chronic diseases.

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* Sexually Transmitted Diseases

Northwest Territories

AIDS education has been incorporated into the Family Life Unit of the School Health Program, and this has been mandatory for junior high students since September, 1987. AIDS education is compulsory for grade eleven, but not for grades ten and twelve.

A draft program, using local resources and people, and Bill Yarber's book* as background material, was developed a year ago. Workshops included one teacher from each school and a nurse. The revised version is now in the process of its final printing for use in grades seven to nine in September, 1988.

Senior High Schools (which follow the Alberta curriculum) will initiate the use of the program, "Career and Life Management" in September, 1988.

AIDS is discussed very briefly in grade four as one of the many communicable diseases, is omitted in grade five, and is formally introduced in grade six.

There is a strong emphasis on individual responsibility and on how the disease can be prevented (rather than on how it is transmitted), and the program is presented in a positive way as an opportunity to assess personal life styles and values. Special consideration was given to the language in order to foster a warm communication with the students and to make sure that the subject matter was interesting and understandable, and at their own level.

There are some multi-grade classrooms, in which case classes on AIDS will often be taught as one class.

Policies and Guidelines

AIDS education was made mandatory in Junior High School as part of a general government policy. Recently the AIDS program has hired an AIDS Consultant to develop AIDS policies for several government departments, including the Department of Education.

In 1986, the Department of Education issued guidelines which stated that school staff and schoolchildren who are HIV infected will be assessed on an individual basis, and recommended the need to protect confidentiality.

Training

There are seventy-three schools in sixty-five communities, and communities are isolated. Teachers in each community have received in-services on teaching AIDS in schools.

Parents

Parents may opt their children out of the AIDS program, even though it is mandatory in the schools.

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* "AIDS, What Young Adults Should Know", by Dr. William Yarber, Douglas and McIntyre (Educational) Ltd., Vancouver, B.C., 1987.

They are, however, encouraged to participate. Parents are consulted throughout the school year, and some districts have held meetings and shown samples of the children's work. One of the strengths of the AIDS program in the Northwest Territories is the team work between the variety of professionals, community elders and the general public. The Departments of Health and Education have taken joint responsibility for educating parents about AIDS. (The Department of Health Family Life education consultants have generally acted as resource leaders, and the Department of Education teacher consultants have provided information services.)

Parents wishing to discuss their concerns privately are given the opportunity to do so.

School AIDS Course also used for Adult Programs

The AIDS school program has also been adapted for use with adults, in particular with an Alcohol and Drug Abuser group, and was found to be very helpful in eliciting feelings and intuitive insight.

Nova Scotia

AIDS Education

AIDS education was made mandatory in the secondary schools of Nova Scotia in May 1988. Beginning in September, 1988 all grade 7-12 students will receive AIDS education.

AIDS education is an integral component of the mandatory Personal Development and Relationships life skills program at the junior high (7-9). AIDS is included in the Sexually Transmitted Diseases component of the program. Program support includes student and teacher materials and numerous audio-visual resources.

Guidelines and Resource Materials

The Department of Education has developed AIDS education resource packages for all high schools. These packages include guidelines, teaching suggestions, and student learning activities. These are supported by audio-visual and print resources. The Department has provided and continues to provide in-services on AIDS education.

In-Service Training

At the elementary level (P-6) the Department will begin provincial in-services in November 1988 for all district boards. These in-services will help elementary teachers become more knowledgeable about AIDS and more comfortable in handling children's questions about AIDS.

Ontario

AIDS Education

AIDS education has been made mandatory in grades seven and eight, and there is one compulsory unit in the secondary school health education program, grades nine to twelve.

The City of Toronto Public Health Department has developed a comprehensive AIDS education Plan for 1987-1989.

Training and In-services

The teaching of teachers is a very important provincial focus. The Ministry of Education has prepared resource documents for School Board use. These include five booklets for teachers, giving information about the courses, and details of available resources.

The resource kit "Education About AIDS" includes documentation on:

- General information
- General teaching strategies
- Teaching strategies for grades 7 & 8 physical and health education
- Teaching strategies for the grades 9-12 physical and health education
- Transparencies.

The Ministry of Education has also prepared video materials, resource documents, and implemented TVO workshops for teachers across the province.

Parents

The Ontario Public Education Panel on AIDS has produced Fact Sheets, "Information for Parents and Teachers", and "A Guide to Organizing a Parent Information Session on AIDS and HIV Infection". Another major concern is to reach the parents through the mass media campaign and workshops.

Funding of STARR

A theatre group consisting of young adolescents, "Students Talking About Responsible Relationships", (STARR), will do skits on sexuality and AIDS for grade seven and eight students in some Toronto schools.

New Resources

The Ministry of Health is developing a video, with a teacher's guide and student handbook, for use in grade seven and eight classes.

In addition, the ministry has funded Trinity Theatre, Toronto, to develop an AIDS education drama for use in the schools and for presentations to adults.

Prince Edward Island

Ontario Educational Materials

The Department of Education has provided all High School students (Grades 9-12), parents and teachers with a two-page educational sheet on AIDS based on material from Ontario (developed by the Ontario Public Education Panel on AIDS).

Guidelines for Schools

The Ad Hoc Committee for AIDS Education has just completed its research on guidelines for schools.

Family Life Course

A Family Life Course is being piloted in September, 1988, and it will include a component on sexually transmitted diseases. AIDS will be taught briefly in grade eight and in greater detail in grade nine.

There are plans to implement the course in all schools in September 1989.

Public Health Involvement in Home and School Association Meetings

The Public Health Association offered a grant for the production of a live dramatic presentation on AIDS, in support of PEI Home and School workshops. The production was devised by Ron Irving's Theatre, PEI, and was very successful. The grant has now run out, but the play was videotaped, and can be obtained from the audiovisual section of the Department of Education.

Parents

The Home and School Association has also met to view the film "The New Epidemic", and has held discussions on AIDS.

Quebec

There is no compulsory AIDS education in the school system.

Individual school boards have developed their own policies and guidelines.

The Protestant School Board of Greater Montreal produced a detailed teacher's manual for AIDS in 1986. It includes an analysis of ethical-legal implications and current legislation in Quebec.

Saskatchewan

AIDS Education

The Department of Education has prepared curriculum materials on AIDS for use in the Health Curriculum, Sexually Transmitted Disease section in Grades 8 - 9.

The Department's materials are strongly recommended to school boards. Each school board determines if the curriculum is to be taught in the schools.

A curriculum module for grades 10 - 12 is under development and is targeted for distribution in January 1989.

Evaluation

The Saskatchewan Teacher's Federation has taken a part in reviewing the new AIDS course, and was active in developing AIDS policies in the field of education.

Training

In-services have been given to teachers, and some of the health teachers have been involved in field tests.

Pamphlets

A series of pamphlets has been written for schools and day care centres.

Yukon

AIDS Education

Originally the Family Life Co-ordinator offered a course on AIDS in the schools if the school board invited her to come. When British Columbia made its program mandatory, the Yukon followed suit to bring it into line with B.C., and this is considered to be a major step forward.

AIDS has been incorporated into the Family Life Program, at the Grade seven level. There is some flexibility about how the subject is treated. It includes discussion on the use of condoms, "but the basic message is 'Say no!'" The curriculum is based on B.C. materials.

Training

The Family Life Co-ordinator is now teaching the teachers, and has her own materials, which are different from the health training materials (she is geared to teach children).

Parents

There are no specific AIDS programs for parents, apart from open meetings through the schools. Any parent wanting personal information would phone the Communicable Disease Officer at Whitehorse General Hospital.

Summary

One of the most important features of all the provincial and territorial AIDS programs has been the introduction of AIDS teaching into the schools, the instruction of teachers and the maintenance of on-going AIDS education for young people.

There is some variety in what has been implemented.

National/Federal two-phase consultation project began 1988.

AIDS education begins at Grade 4:

Northwest Territories (very briefly: introduced formally in grade 6)

AIDS education begins at Grade 6:

Northwest Territories

AIDS education begins at Grade 7:

New Brunswick, Ontario, Alberta, Manitoba, Saskatchewan, Yukon, British Columbia, Nova Scotia

AIDS education begins at Grade 9:

Newfoundland (but younger grades include informally)

AIDS programs recently having been/being pilot tested:

Prince Edward Island (for grades 8 & 9, pilot-tested Sept. 1988 for inclusion in schools Sept. 1989)

Alberta (for senior high schools, pilot tested 1987/88, to be implemented in schools 1988/89.

Saskatchewan (high schools) to be pilot-tested Sept. 1988, and distributed Jan. 1989.

New Brunswick (grade 7 up) Anglophone curriculum pilot-tested in some areas in 1987.

Nova Scotia (grades 7-8) pilot-tested 1987/88, to be implemented Sept. 1988 (grade 7); Sept. 1989 (grade 8); Sept. 1990 (component grade 9).

AIDS education compulsory:

Ontario (grades 9 - 12), Manitoba (grades 7-9); Northwest Territories (grade 11)

AIDS education mandatory:

Ontario (grades 7-8); Yukon (grade 7 - up); British Columbia (grade 7-up); Manitoba (grades 10-up); Northwest Territories (junior high school); Nova Scotia (grades 7-12)

AIDS education neither compulsory or mandatory:

New Brunswick, Prince Edward Island, Quebec, Alberta, Saskatchewan, Newfoundland.

Basic education (no emphasis on values):

New Brunswick

Denominational teaching:

Newfoundland

Values a focus:

Alberta, Newfoundland, Saskatchewan, Northwest Territories

Responsible decision-making a focus:

British Columbia

Theatre groups:

Ontario, Prince Edward Island

Teachers should be comfortable:

New Brunswick, Saskatchewan, Northwest Territories, British Columbia.

Particular Focus on parents:

Newfoundland, Prince Edward Island, Ontario, Manitoba, Saskatchewan, Northwest Territories, British Columbia.

Family Life Education for use at home:

British Columbia

Special materials produced for parents:

Ontario (OPEPA Fact Sheets); Manitoba (Booklet); British Columbia (Family Life Curriculum for home; pamphlet)

Teacher training:

Basic, no values training: New Brunswick

Strong public health involvement: Newfoundland, Prince Edward Island, Alberta, Manitoba, British Columbia.

Many extra resources: Newfoundland, Ontario, Alberta.

Guidelines:

Alberta, Manitoba

National

> "HIV infection creates an issue in the workplace for two distinct groups of people: those who are infected and those who fear becoming infected. The main issue for those who are infected is discrimination, and, for those among them who have AIDS, workplace accommodation to their needs as employees with a disease. The main issue for those who fear becoming infected is the right to safe working conditions. These interests are protected on the one hand by human rights legislation and on the other by occupational health and safety legislation, and these may not always be wholly reconcilable. In most workplaces the risk of infection is so low that the human rights perspective ought to prevail. In the case of HIV infection, society must choose which interests are to be preferred, basing its choice on evidence and not on fear or speculation.
>
> Employees often mistrust assurances that AIDS does not create risk in the normal workplace . . . .
>
> . . . . We recommend that every workplace develop education programs tailored to the conditions of the workplace and designed co-operatively by management, unions, employees and occupational health and safety representatives". . .

(*AIDS: A Perspective for Canadians, Summary Report and Recommendations*, Royal Society of Canada, April 1988)

On May 25, 1988, the Human Rights Commission published a communiqué extending AIDS protection. "People who suffer discrimination because of groundless fears about AIDS can now look to the Canadian Human Rights Commission for protection.

"Chief Commissioner Maxwell Yalden announced today that the Commission has opened the door to complaints from two new groups" – people who are not HIV infected but have been discriminated against because of their association with people who are HIV infected (family and friends, for example), or because they belong to groups which are widely regarded as being vulnerable to HIV infection (homosexual and bisexual men, Haitians and persons with haemophilia, for example) . . . .

"The Commission recognizes three genuine occupational requirements that may justify treating employees infected with HIV differently than other employees, where:

- they carry out "invasive" procedures (that is, "Procedures including puncture or incision of the skin or insertion of an instrument or foreign material in the body") as an unavoidable part of their work;
- they must travel to countries which bar entry to people who test positive for HIV antibodies in the blood.
- sudden deterioration of the brain or central nervous system would compromise essential safety requirements.

People in these three categories may be tested for HIV infection.

However, the Commission takes a stand against the across-the-board testing of employees.

"HIV positive reaction does not affect the ability to do most jobs," Mr. Yalden said. "There is no public health reason to invade people's privacy in this way without their consent and without good reason for doing so."

"The policy also recognizes a legitimate justification for refusing a service to someone infected with HIV when it would require invasive procedures which result in exposure to blood or blood products, and the risk is real despite all reasonable precautions.

Objections by co-workers to mixing with people infected with HIV will not be accepted by the Commission as adequate reason on its own for discriminatory treatment."

The Commission already takes complaints from people who say they have been discriminated against because they are infected with HIV, and is at this time investigating the case of a bank employee in Ontario and a cook in Manitoba who have alleged that they have lost their jobs for this reason.

(From Canadian Human Rights Commission Communiqué, Ottawa, May 25, 1988)

On May 16, 1988, the Annual Meeting of the Canadian Association of Statutory Human Rights Agencies (CASHRA) ratified a series of resolutions directed towards all governments of Canada, among them one on AIDS:

- "CASHRA resolves to urge all governments of Canada to follow up on dealing with AIDS as a disability requiring the support and empathy of the community. To this end, educational and other support systems would be put in place; it will decrease the suffering and isolation of persons with AIDS, their families and loved ones." (News Bulletin of the Human Rights Commission, Whitehorse, Yukon.)

Federal

AIDS in the Workplace - Bureau of AIDS Prevention and Services Programs

The Federal Centre for AIDS is developing a manual specifically for small business. This initiative is meant to encourage small business operators and owners to find out the facts about AIDS and the rights of their employees who may have AIDS or who are seropositive. Our goal is to make the process of developing an AIDS policy and educating employees about AIDS as easy as possible for the small business owner/operator. The manual will also identify relevant education resources to further assist the small business owner/operator.

(From Federal Centre for AIDS Communications and Education Services, Education Programming Update Jan.-May 1988).

Alberta

Employment policies and legislation

There is no new legislation for AIDS in the workplace, and the government policy is one of non-interference.

Human Rights legislation prohibits discrimination on the grounds of disability, but this has not yet been tested in the case of HIV +. Discussions are under way with the Alberta Human Rights Commission to prevent discrimination against those who are infected.

The Public Health Act precludes the embalming of people who have died of AIDS.

Employers

Employers are encouraged to form their own policies. The Department of Health provides in-services and education programs in the workplace, designed to increase understanding and lessen fears about AIDS, and to effectively link activities at both the provincial and local levels.

The provincial AIDS program, "Education and Caring: Alberta's Program for AIDS" recommended the hiring of an AIDS Workplace Consultant for six months, to up-date materials, identify present and future needs and to act as a source of information and advice (Goal IV, Obj. 1, Strategies 1-3). This has occurred, and not only has an AIDS Workplace Consultant been hired, but a more permanent position is under consideration.

The same document focuses on the need to inform employers and workers of the appropriate precautions to employ to prevent transmission of infection in the workplace (Goal II, Obj. 2.4, Strategies 1-4). It commented on the fact that people tend to be slow to use safety precautions, and that there is a need for continuous up-dating and reinforcement. It also recommended follow-up procedures to determine the occurrence of workplace risk factors (Goal VI, Obj. 6.2, Strategies 1-3).

Hospitals

The comprehensive public education program which is under way provides for the provision of on-going education for physicians and health care workers by STD control, other health professionals, The Speaker's Roster, and members of self-help groups. The purpose is to increase the knowledge of transmission and infection control, and to increase awareness of psycho-social issues and capability in caring for patients with HIV infections and AIDS.

The Department of Community and Occupational Health has developed education packages for health-care professionals.

There are no government regulations regarding the right of health care workers who are infected with the HI virus to work. All hospitals have their own policies, and such employees would in any case be very difficult to identify. Employers are advised, as part of a general AIDS directive, to treat employees as if they are able to work until such time as it becomes apparent that they are unable to continue to do so satisfactorily.

Emergency and other services

Guidelines are being prepared by the Occupational Health Consultant.

Funeral Homes

The Public Health Act includes AIDS under the "Dead Bodies Regulation", and funeral homes have been prohibited to embalm people who have died of AIDS. This legislation has become very controversial, and some families have been upset.

Schools

Teacher training is provided through seminars given by the STD Education Division with the co-operation of Alberta Education. Teachers are being given increased opportunity to expand their knowledge and skills, and to examine their attitudes towards AIDS issues, and this will be part of on-going training. A government position is that staff will continue their work as long as they are well enough to do so, as with any other disease.

Confidentiality

The regulations governing confidentiality vary according to the situation and who is involved. Civil servants, for example, are required to sign a declaration of confidentiality, and people in networks have their own ethical guidelines and rulings.

A joint statement was issued from Alberta Community and Occupational Health and Alberta Education Departments containing guidelines based on the recommendations from the U.S. Centres for Disease Control.
The document "Education and Caring: Alberta's Program for AIDS" (Alberta Community Occupation and Health, Oct. 1987) discusses the medico-legal issues related to testing blood, and the need for the utmost confidentiality (Goal 7, Obj. 7.2 and background pages 23-24) and also the right of those who wish to be tested to do so anonymously.

British Columbia

Employment policies and legislation

There is no new legislation for AIDS in the workplace. The issues are theoretically covered by existing laws, but there is some doubt as to whether this protection is adequate.

Medical care comes under the Human Rights Act.

The Attorney General's Office has recognized AIDS to be a disability, so that people with AIDS are protected by the legislation for the disabled.

Human Rights legislation has not been amended to include AIDS specifically.

The Ministry of Health guidelines "AIDS Information for the Workplace" includes a Health and Safety Division Directive covering the refusal of a co-worker to continue to work with an individual who is infected with the AIDS virus, and states that the decision "will be reasonably accommodated to the extent that the refusal is based on a reasonably held belief" and that it is possible to offer "a re-assignment of duties if such action is deemed warranted." (Personal Management Policies and Procedures, page 3, Section # 8.1, 01-10-87)

The City of Vancouver Health Department Guidelines "HIV, AIDS & The Workplace" introduced new policy guidelines on the management of persons with HIV infection in the workplace with an education program about AIDS and HIV. The statement includes "If an employee refuses to work with a person with AIDS then the relevant disciplinary action will be taken as a last resort." (Basic Answers and Questions, p. 4)

Employers

The Ministry of Health is chairing an inter-disciplinary committee which is developing guidelines for dealing with AIDS in the workplace. The guidelines will be available to all employers who are interested in developing an internal policy on AIDS. The committee is composed of representatives from labour unions, employer groups and private industry.

The City of Vancouver Department of Health has produced guidelines, "HIV, AIDS & The Workplace, Guidelines for managing persons with HIV infection in the workplace."

The province has developed a Workplace Package for AIDS, which includes a Manager's Manual and an employee's package. There are very detailed instructions on how to train and give workshops on AIDS. It includes three pamphlets on general information, long-term disability programs and First Aid. It also encloses government recommendations, policies and guidelines. It was released in March 1987, and is available throughout the province. It is already going into another printing, and has proved to be very popular (at least 10,000 have already been sent out).

Hospitals

Ministry of Health employees have participated in numerous workshops and hospital presentations on AIDS.

The Ministry of Health also produced pamphlets for physicians and health care providers, "AIDS: Important Information for Health Care Providers" which includes information for laboratory personnel, and "Information for Physicians on AIDS and Human Immunodeficiency Virus (HIV) Antibody Testing" (a companion pamphlet to one produced for persons wishing to be tested).

Emergency and other services

The province is moving towards universal guidelines, but it varies according to local viewpoints.

Funeral Homes

The National recommendations have been adopted for funeral homes. There has been a problem over the issue of morticians preferring not to embalm people who have died of AIDS, but a couple of funeral homes still provide this service.

Schools

The B.C. Ministry of Health distributed guidelines to school boards, "HIV Infections – Guidelines for the Management of Persons in Educational Settings." Essentially, school and medical health officials will treat each AIDS case as an occupational matter. School employees who are HIV infected may continue to work if they can do so satisfactorily. If their condition deteriorates, the school board may relieve them of their duties, and this could be a temporary arrangement. The employee would be covered by the normal procedures for sick leave, and prolonged or continuous absences would be dealt with under the School Health Act. (Canadian School Trustees' Association Fact Sheet)

Confidentiality

There is no new legislation for confidentiality for AIDS, and existing legislation has been thought to be adequate, although this is now being questioned. There has been no test case brought to court.

Employers must maintain confidentiality, but there are no specific penalties for breach of confidence.

The Ministry of Health Guidelines "AIDS Information for the Workplace" emphasizes the need to observe strict confidentiality when dealing with employees who are HIV seropositive, and includes directives developed for the Health and Safety Division under the Public Services Act. The Vancouver Health Department also urges confidentiality in its guidelines "HIV, AIDS & The Workplace, Guidelines for managing Persons with HIV in the Workplace."

A Ministry of Education Policy Circular urged school boards to implement policies and procedures to deal with AIDS, and to meet with the local school medical officer and also, perhaps, the medical officer of health, to discuss the implications of AIDS for students and employees. (Canadian School Trustees' Association Fact Sheet)

Manitoba

Employment policies and legislation

There have been no new policies or legislation created specifically for AIDS in the workplace. The Human Rights Act protects the disabled from discrimination, and this is understood to cover AIDS, although it has not been amended to do so.

Guidelines have been distributed according to categories of work, that is, for people dealing with emergencies, for the hospital and for the general workplace.

It is expected that no one would refuse to provide a person with AIDS with services, or to work with them.

Workplaces are not being advised to provide infection control kits as a general rule; some have added gloves to their First Aid kits.

Employers

Guidelines entitled "Interim Guidelines for the Workplace" have been distributed to the general workplace, and one of Manitoba's targets for 1988 is the education of managers in the workplace.

Health Department in-services have been provided to employers who have requested this, on a province-wide basis. There is no charge involved. There has been such a demand that it has been difficult to respond to the number of requests.

If employers wanted an in-depth counselling service, they would have to pay for it; but there have been no formal requests for this kind of AIDS education yet.

In-services concentrate on the provision of basic information, but they are also geared to what the group already understands, so that there is considerable flexibility in the way materials and information are presented. There is an effort to help participants come to grips with fears about AIDS. Policy development is also an integral component of such sessions.

Hospitals

Each hospital has its own guidelines about the employment of HIV infected health care workers. However, they generally adhere to the provincial "Interim Guidelines for Hospitals." There is a provincial policy for this and government thinking is consistent with the Laboratory Centre for Disease Control (LCDC) and Centres for Disease Control (CDC) Atlanta policies. There has only been one case of a person who was HIV seropositive working in the operating room and so there has been very limited experience in confronting this issue.

Department of Health guidelines have been distributed to hospitals and health care workers. A series was produced, among them:

- Interim Guidelines for Hospitals, Laboratories and Pathologists
- Interim Guidelines for Home-care Providers and Long-term Facilities

Emergency and other services

Police, firemen, and ambulance workers were all provided with guidelines in 1987. Part of a series for the workplace, emergency care guidelines are entitled, "Interim Guidelines for Resuscitation Training and Providers of Pre-hospital Emergency Care."

Funeral Homes

Funeral homes were provided with guidelines in 1987, entitled "Interim Guidelines for Funeral Directors."

Correctional Facilities

Correctional facilities were provided with Guidelines in 1987, entitled "Interim Guidelines for Correctional Facilities and Detentional Facilities."

Schools

The Department of Health produced Guidelines for schools and day care centres, entitled "Interim Guidelines for School and Day-Care."

The Canadian School Trustees' Association circulated an information sheet about the procedures adopted by the St. James Assiniboia School District No. 2 for its schools' use, entitled "Communicable Diseases – AIDS Students/Employees Diagnosed as Having AIDS (HIV-III/LAV)". It includes the statement, "Where the physical condition or behaviour of an employee infected with the AIDS virus poses a health risk because of the AIDS virus related condition, that person may be excluded from employment. Regular employee benefits such as salary continuance or other sick leave provisions will apply." (Employees 3)

Other school divisions have adopted less stringent approaches.

Parents do not have the right to remove their children from school because of the fear of being exposed to a person who is HIV infected. The Schools Act requires every child to attend school.

Confidentiality

There has been no new legislation covering confidentiality or the "right to know". There are no penalties for breach of confidentiality; this would have to be resolved as a private civil suit.

The document "Communicable Diseases – AIDS Students/Employees Diagnosed as Having AIDS (HIV-III/LAV)" includes recommendations about confidentiality for students and school employees, the "need to know" and counselling of "those who have been told."

Final provincial guidelines for schools are awaiting approval; for the present, school divisions are developing guidelines based on interim provincial guidelines.

The various guidelines distributed to the workplace by the Department of Health discuss confidentiality and ethical questions related to AIDS.

New Brunswick

Employment policies and legislation

The right to work is provided for under the Human Rights Act. There is no new legislation specific to AIDS, but it is thought that people with AIDS would be protected under the section of the Act which deals with the disabled.

Policies are under development by the Occupational Health and Safety Commission. Legislated policies such as the right to refuse unsafe work and the "right to know" are being examined closely in the context of AIDS. In general, the feeling is that in most workplace settings there is essentially no risk of transmission of AIDS, based on the fact that casual transmission has not been associated with infection. In health care settings, individuals are encouraged to be aware of the appropriate precautions to take whether or not a person may be infected with HIV; if individuals are following recommended precautions, then the actual threat to the worker is not felt to be significant.

Employers

Policies are being developed by government, various associations associated with government, and by private businesses. Many hospitals have also identified policies which are appropriate to follow.

Requests from the New Brunswick Telephone Company and the New Brunswick Hospital Association have been responded to by the dispatch of information and a training package from AIDS New Brunswick, and they will deal with the training of their employees through their own management.

Department of Education guidelines have been developed to standardize information on awareness and education programs for specified occupational groups.

Hospitals

Each hospital makes its own decisions about policies and regulations, and there are no specific government policies about the employment of hospital workers who are HIV infected. The guidelines for universal precautions as promoted by the Laboratory Centre for Disease Control are being adopted in many hospitals around the province.

The Department of Health has developed guidelines for standardized information on awareness and education programs for health care workers.

Emergency and other services

Some information has been made available to firemen, police, ambulance and other services. They are encouraged to follow blood and body fluid precautions when appropriate.

Funeral Homes

Guidelines for morticians are those promoted by the Laboratory Centre for Disease Control. The Association of Funeral Directors has been meeting with Department officials to examine policies with respect to infection control procedures, whether it is necessary to know specific information about infectious diseases a person may have had, and so on.

Schools

The Department of Education developed a policy statement with respect to employees and students, "The AIDS Virus and Public Schools: Draft Policies and Operating Guidelines." Policy 5.0 states that an employee cannot be excluded from his/her employment because of AIDS infection unless the District Medical Officer advises. 5.4 continues that an uninfected employee who has a family member with AIDS virus infection cannot be excluded from employment for this reason. The policy statement also deals with other aspects, such as AIDS education for staff as well as students. (Canadian School Trustees Association Fact Sheet)

Confidentiality

Confidentiality of medical information is of great concern. The Department has been examining existing provisions. For example, hospital patient information is confidential and is legislated under the Public Hospitals Act. Similarly, information on cases which is reported to Medical Officers of Health is covered by confidentiality provisions under the Health Act.

Present regulations dictate that anyone knowing an individual is infected with HIV, or has ARC or AIDS must report to the District Medical Officer of Health. The name and other appropriate information must be provided. Detail on the names of individuals remains with the District Medical Officer of Health while overall statistics are passed on to the Provincial Epidemiologist for collation.

Physicians are encouraged to use codes on laboratory forms rather than names of individuals in order to preserve confidentiality. Some consideration may be given in the future to some sort of non-nominal reporting system.

Decisions about "who has the right to know" have presented a constant challenge. The Department of Education developed a policy in 1987, and this is being confirmed at an inter-departmental level. It will essentially seek to limit the people who "need to know" to those who are significantly at risk, and will be under the control of the Public Medical Officer of Health.

There are no specific penalties for breach of confidence. A case of this sort would involve a private civil suit.

The Department of Education policy statement, "The AIDS Virus and Public Schools: Draft Policies and Operating Guidelines" stipulates the maintenance of confidentiality for students, teachers and other employees (Policy 1.0 and 4.0) (Canadian School Trustees Association Fact Sheet) and also gives guidelines on "who needs to know" (Policy 1.0, 1.2 and 4.0, 4.1, 4.2, 4.3).

Newfoundland

Employment policies and legislation

There has been no new AIDS legislation for the workplace, but the right to work is provided for under the Charter of Human Rights and the Newfoundland Human Rights Code.

Guidelines will soon be issued about some restrictions for people who have AIDS or are HIV seropositive. These will not be legislative at this time, and they deal with certain medical conditions.

A government employee would not have the right to refuse to work with a person who is HIV infected.

Employers

Employers wanting information or help in forming internal policies would be aided by the Medical Officer of Health or some other provincial staff member. This would be at their own request, the public health authorities do not require employers to conduct AIDS education programs. So far the Health Department has been approached by a number of companies for information.

There is an education package for the workplace which includes the facts, myths and misconceptions about AIDS. There is a talk first, and this is followed by the opportunity for an open discussion. There is not an initial focus on fears and prejudices, but these would be addressed during the discussion period if they were introduced as topics of interest.

Hospitals

There is a policy for health care workers who are HIV seropositive. This has been stated in the guidelines which have been drawn up and sent to major hospitals by the Provincial Advisory Committee on AIDS. It places some restrictions on people who are HIV infected and have certain medical conditions.

Pre-employment screening for hospital workers has been looked at but it is not being recommended.

The Department of Health has provided information kits for physicians.

Emergency and other services

Police, firemen, Red Cross workers, ambulance personnel and the one forensic medical worker have all received some sort of AIDS information. Public Health workers have been provided with in-services. Firemen have also received resuscitation mouthpieces, and infection control kits and gloves have been distributed throughout the workplace as suitable to the situation.

The ambulance drivers who are stationed at the hospitals have been in-serviced, and there has been some in-servicing for privately-owned ambulance companies. Rural ambulance services have not received the same level of AIDS education because they are more difficult to contact, and they simply provide a bed and driver.

The Red Cross workers are trained through their own organization, and follow national guidelines.

Food handlers were given in-services through the Public Health Inspection services. Guidelines and pamphlets have been delivered to them, and they regularly undergo inspection.

Blood and Body Fluids precautions are being advised where this is applicable.

Funeral Homes

The Department of Health met with the Funeral Directors Association, and funeral staff have received in-services. For the last 18 months, they have been regularly in touch with the Department of Health.

Schools

The Department of Education has published "Guidelines for the Development of School Board Policies on AIDS" to assist school boards to form policies about AIDS. It recommends that the student may not be excluded from school unless circumstances warrant it (Policy A, 2 and 3) and that an employee may continue to work unless not well enough to do so effectively. Both psychological as well as physical health must be taken into account in assessing capabilities (Policy B, 5).

Any employee who is excluded from work because of AIDS must be dealt with according to the provisions of the applicable collective agreement or employment contract. (Canadian School Trustees' Association Fact Sheet)

Parents do not have the right to keep their children out of school because they are afraid of a possible contact with someone who is HIV infected, and they could be held legally accountable if they attempted to do so.

Confidentiality

There is nothing explicit about confidentiality and "the right to know" for employers in general, and a breach of confidentiality would have to be settled through civil action. There has not yet been a test case.

The Department of Education "Guidelines for the Development of School Board Policies on AIDS" strongly recommends the maintenance of confidentiality for students and school employees (Policy A1 and B4) and suggests that the board should review the policies at least once annually, and keep abreast of current information on AIDS. (Canadian School Trustees' Association Fact Sheet)

Northwest Territories

Employment policies and legislation

There are no provincial guidelines about the right of an individual who is HIV seropositive to work.

There is a person on contract to draw up a draft policy, and that should be completed by the end of June 1988.

Employers

After the Government of the Northwest Territories policy is in place, it is expected that departmental activities to write protocols or guidelines will follow. The government policy will serve as a model for private employers in the NWT.

Hospitals

Copies of the Manitoba guidelines are on hand, and hospitals have guidelines in place.

Emergency and other services

Copies of the Manitoba guidelines are on hand for emergency services, and the St. John Ambulance and other services have guidelines in place.

Schools

The Department of Education has developed guidelines for teachers and students.

Confidentiality

The issue of "Age of Consent" for medical treatment is currently being reviewed, and may have implications for the notification of parents.

Nova Scotia

Employment policies and legislation

There is no new legislation for AIDS in the workplace.

The Department of Health and Fitness produced a brochure "AIDS and the Workplace" which makes recommendations about employment issues and gives information about infection control for AIDS.

Employers

Some large organizations have AIDS policies in place. Most of these are national companies who have instituted AIDS policies in all their branches.

The majority of school boards have also developed policies, which are already in effect.

The brochure produced by the Department of Health and Fitness, "AIDS and the Workplace" (based on an Ontario Fact Sheet) will be distributed to all provincial government employees, and will also be made available to industry. It makes general recommendations about maintaining an employee in the workforce if that person is capable of working effectively (but with sensitivity to episodic bouts of severe infection and the need to find alternative types of work under these circumstances); safety of co-workers and customers; that employers do not have the right to insist on mandatory testing; how to enquire about AIDS education programs for employees.

Hospitals

The Department of Health distributed guidelines for health care workers and medical personnel for handling AIDS:

"Guidelines for handling patients with suspected or confirmed Acquired Immune Deficiency Syndrome (AIDS)" (Jan. 1985)

"AIDS surveillance and health care workers" (April 1985), distributed to Hospital Infection Control/Occupational Health Officers/Nurses

"Screening for AIDS and Mandatory Reporting" (Oct. 1985), distributed to all physicians in Nova Scotia

"Medical Guidelines for HIV Screening" (Nov. 1987)

"Medical Guidelines for the Management of Exposure to Blood/Body Fluids"

"Routine Precautions for Staff and Students Exposed to Blood/Body Fluids"

"Information for Physicians on the HTLV-III Antibody Test" (a joint project with the Medical Society of Nova Scotia) (Oct. 1986)

Emergency and other services

The Department of Health and Fitness brochure "AIDS and the Workplace" makes general recommendations for infection control of AIDS for health care workers, ambulance drivers, police officers, emergency workers and personal service workers (barbers and manicurists).

The Department of Health and Fitness "Guidelines for Handling Patients with Suspected or Confirmed Acquired Immunodeficiency Syndrome (AIDS)" (Jan. 1985) covers infection control procedures for laboratory personnel and personnel performing autopsies.

Funeral Homes

The Department of Health and Fitness "Guidelines for Handling Patients with Suspected or Confirmed Acquired Immunodeficiency Syndrome (AIDS)" (Jan. 1985) covers infection control procedures for "persons performing Necropsies or providing Morticians' Services."

The guidelines produced by Centres for Disease Control, Atlanta, Georgia were distributed through the Canada Diseases Weekly Report.

Schools

The Department of Health and Fitness distributed guidelines "Control of HTLV III/LAV in School Aged Children" (Jan. 1986) and "Routine Precautions for Staff and Students Exposed to Blood/Body Fluids" (Jan. 1986).

Many school boards have developed policies dealing with infection control in schools and with staff or children who have developed HIV infection.

Confidentiality

There is no specific legislation related to AIDS.

The Department of Health and Fitness brochure "AIDS and the Workplace" mentions that "the person with AIDS has a legal right to privacy and confidentiality" and that "employers, co-workers and neighbours are not required to be informed of an individual who has AIDS" . . . . "An employer can only request medical information that is relevant to his or her job. An employer can only confirm this information with a physician with the employee's expressed consent."

Hospital and provincial staff are required to maintain confidential personal information they have access to.

Many school boards have included the protection of confidentiality for both staff and children in their policies, as well as defining "who has the right to know".

Ontario

Employment policies and legislation

The right to work is protected under the Human Rights Code. People with AIDS or who are HIV seropositive may continue to work if they are both physically and mentally capable of doing the job effectively. This is monitored by the individual's private physician, the medical officer of health, and sometimes a professional organization is involved (if, for example, the PWA is a social worker and a member of the Social Worker's Association).

Employers are legally forbidden to require pre-employment screening, and confidentiality is protected under the Health Protection and Promotion Act. No specific penalty has been imposed for breach of confidentiality. This issue would involve a civil suit under the Human Rights Act and the Health Protection and Promotions Act, and there have been no lawsuits to date.

Under the Occupational Health and Safety Act, employers must provide a safe work site and appropriate protection from harm, and the possible case of a co-worker's refusal to work with a person with AIDS is tied to this regulation. Under most circumstances, an employee who refused to work with a PWA could be fired unless it could be proved that there was personal danger involved. Alternatively, there is responsibility on the part of the employer to provide adequate protection for the employee, and a grievance can legally be filed if it can be proved that this has not been complied with.

Employers

Guidelines have been developed for the workplace, and a manual is being produced, together with an educational package. Education for the workplace has been a major focus of the AIDS program. The City of Toronto Public Health Department has developed a workplace AIDS education program for staff which will serve as a prototype for the private sector, and has given presentations to various workplaces and professional organizations.

The Ministry of Health, in conjunction with the Ontario Public Education Panel on AIDS (OPEPA), produced and distributed fact sheets on "AIDS and the Workplace".

Employers have been encouraged to develop their own policies and programs. Although they would handle the costs of this themselves, they are given as much help as possible through the Speaker's Referral Service and Public Health teams. They are supplied with Fact Sheets, brochures and sample copies of policies written by other companies and jurisdictions. They may also borrow materials and resources. Since each work site is different, employers are helped to develop what is applicable to their own situation. Certain legal points are emphasized to them (for example, that pre-employment screening is against the law).

Workplaces are not being advised to have infection control kits except as a general measure of advice. If First Aid kits are in use, it is suggested that one person be trained to take responsibility, and that the training should be directed to the control of general infection (not specifically just AIDS infection). Also, if there are infection control kits in use, they should be accessible (for example, school football teams should have kits available on the field, not just in the school).

There are no specific policies for health care workers who have AIDS or who are HIV infected. Each hospital develops its own policies and regulations for its workers.

The Ministry of Health produced two booklets for professionals, "AIDS and HIV Infection: Psychological Issues and Information for Professionals" and "Understanding AIDS and HIV Infection: Information for Hospitals and Health Professionals."

The Ontario Public Education Panel on AIDS also produced Fact Sheets on "AIDS and Health Care Workers,"

Emergency and other services

Health units were funded to provide AIDS education, and these units have provided intensive training, including for police and firefighters.

Funeral Homes

The Ontario Funeral Association issued guidelines for funeral directors with assistance from the Ministry of Health.

Some funeral homes have refused to do embalming, although a few still provide this service for people who have died of AIDS.

Schools

School employees are protected under the Human Rights Act, and both students and staff who are HIV infected may attend school if they are physically and emotionally able to do so. This is monitored by the medical officer of health.

Any child who had to be withdrawn from school would be eligible for the Home Study Program.

Parents would not have the right to withdraw their children from school because of a fear that they might be brought into contact with a person infected with the AIDS virus. Under Ontario law, every child must be registered at school until the age of sixteen.

Confidentiality

There is legislation which provides for confidentiality for a person with AIDS under the Health Protection and Promotion Act, the Human Rights Code and the Occupation Health and Safety Act.

It is legislated that no person shall disclose either the name or any other information about a person with AIDS or someone who is HIV seropositive.

There are a few possible exceptions. Information may be disclosed with the consent of the individual concerned (but this cannot be required). Under certain circumstances, disclosure may be required in a court of law.

The "Right to Know"" is closely restricted.

Prince Edward Island

Employment policies and legislation

There has been no new legislation for AIDS for the workplace. The AIDS Advisory Committee has not produced its report yet, and the government is waiting for its recommendations.

Employers

The Ministry of Health proposed to conduct courses on employers' time, but nothing has been arranged yet.

Hospitals

Each hospital makes its own policies about employment conditions, and hiring and firing policies. There are no government policies about the employment of health care workers who are HIV seropositive.

Emergency and other services

Ambulance personnel follow universal guidelines for infection control.

Funeral Homes

Funeral homes follow universal guidelines for infection control.

Schools

A provincial committee recently presented recommendations to the Ministers of Education and of Health calling for specific directions in dealing with AIDS in schools, and a protocol was designed for school use, concerning the position of students and employees who are HIV infected.

Confidentiality

The statement and protocol "AIDS and the School: Draft Statement on Confidentiality and the Presence of Persons Infected with AIDS in the Schools" affirms an individual's right to privacy, and defines the conditions under which a person has the "right to know". It recommends counselling for this situation, and gives specific "Questions and Answers" which are directed to helping teachers, principals and superintendents answer enquiries about AIDS wisely without betraying confidentiality. (Canadian School Trustees' Association Fact Sheet)

Quebec

Employment policies and legislation

The Working Group on AIDS which was formed in the late fall of 1987 is studying the issues of AIDS Prevention/Education/Ethics and Law/Research/Psycho-social concerns and Hospital Care. It is expected to bring in a report towards the end of August 1988, and is looking at whether it will be necessary to introduce new legislation for AIDS.

Until now the existing legislation has been thought to give adequate protection to people who have been infected with the AIDS virus.

Under the Quebec Charter of Human Rights and Freedoms, an employer can choose to hire an employee on the basis of the aptitude or skills required for the job. People with AIDS or who are HIV infected cannot legally be discriminated against on the grounds of being infected, but if their health deteriorated to the extent that they could not perform the work adequately, there would be legal indications for dismissal. An appeal could be made through the Human Rights organization in cases of doubt. (One argument is that work is therapeutic, and that if possible, alternative work should be offered to accommodate an employee's state of health.) (From "AIDS – A Teacher's Manual", Protestant School Board of Montreal, 1986.)

The Quebec Charter of Human Rights and Freedoms also forbids discrimination against the disabled.

Employers

There is no new AIDS legislation and no new policies have been implemented for employers or the workplace. There has been some discussion, however, about whether airline pilots should be tested, not because they would be likely to infect others, but because the first symptom is frequently dementia.

Hospitals

There is no government policy for health care workers who are HIV infected.

Emergency and other services

No guidelines have yet been developed for emergency services.

Funeral Homes

The Department of Health and Welfare has developed guidelines for funeral homes.

Schools

The Department of Health gave information to the Department of Education about the transmission of AIDS infection in schools, and confirmed that children with AIDS would not normally be infectious to others in school.

Confidentiality

Under the Quebec Charter of Human Rights and Freedoms, an employer need only be made aware of medical facts as they arise and if they are relevant to the employee's work and working conditions.

It is thought that an individual's rights to confidentiality would be adequately protected under the Quebec Charter of Human Rights in its present form, and that no new legislation is needed. However, no legal case has yet put this assessment to the test.

There are policies that confidentiality must be maintained in the schools to protect the identity of people with AIDS.

Saskatchewan

Legislation

Provincial legislation denotes AIDS as being a communicable disease under the Public Health Act, and provisions under that Act deal with negotiations governing control, notification, prevention and treatment of AIDS.

The Department of Education is working on a policy for schools.

The Labour Standards Act would be applied if an employee refused to work with a person with AIDS.

Employers

Employers are being encouraged to provide AIDS education in the workplace. There is presently a focus on developing policies for the workplace. The Department of Health has produced an AIDS Training and Information Manual for the Public Service Commission and has provided an education session for the Human Resource Officers for government departments. A provincial AIDS In the Workplace seminar is currently being planned for employers in Saskatchewan. It will be held in the fall of 1988.

Hospitals

The province has followed NACAIDS guidelines since November 1985 and has accepted that any person with an HIV infection may continue to work as long as they are capable, since there is thought to be no risk of transmission of the disease through normal contact.

Emergency and other services

The Saskatchewan Advisory Committee on AIDS has provided guidelines for health care workers, providers of pre-hospital emergency care, day care centres and schools, and a number of other services.

Funeral Homes

Funeral homes have developed guidelines for use by the industry throughout the province.

Food Handlers

Food handlers are governed by the Communicable Diseases regulations of the Public Health Act.

Schools

The Department of Education and the School Trustees Association have developed a policy to cover issues related to students and staff infected with the AIDS virus. This policy has to be adopted by individual Boards of Education.

Confidentiality

There has been no new legislation.

The government is working with the school boards and school teachers to develop agreement on policies for schools.

Yukon

Employment policies and legislation

There is no specific legislation for AIDS in the workplace. The Public Health legislation in general would apply, but it is very old and it is recognized that it needs to be revised.

There are federal guidelines about the right to work, which state that a person who is infected with the AIDS virus may work unless incapable of doing so effectively. Regulations about screening personnel such as orthopaedic surgeons for the AIDS virus do not apply to the Yukon as there are none. Visiting specialists come to hold clinics periodically. (The Yukon has a general surgeon and an obstetrician/gynecologist.) This question has been looked at in general, but since there have been so few cases locally, it has not been a pressing issue and has not warranted serious consideration. It is anticipated that there would be very few restrictions.

Anyone who refused to work with a person with AIDS after counselling, would probably be asked to leave. At the same time, fears would probably be looked at compassionately and, if it was possible to move the co-worker to another position and the personal situation was favourable, their position might be changed.

The Royal Society of Canada report, "AIDS: A Perspective for Canadians" has very recently been received, and has stimulated thought about AIDS issues.

Employers

Infection control nurses are in touch with workplaces, and have been using federal guidelines. Most employment is through tourism, the government or mines, and there has been no approach from them for a specific policy for AIDS.

Hospitals

Hospitals follow Medical Services Branch guidelines.

Emergency and other services

Ambulance services have been provided with training and guidelines. They are housed within hospital precincts, and a new building is under construction.

Ambulance services for the 12 small communities have also received training and guidelines.

Funeral Homes

There is one funeral home, and it follows the U.S. and Federal guidelines for AIDS. The Communicable Disease Officer is regularly in touch with up-dated materials. There has been no expressed concern about AIDS from the Funeral Director to date.

Schools

There is no legislation for school administrators but there are co-operative guidelines through the Medical Officer of Health.

Parents who felt fearful about AIDS issues would have every opportunity to discuss this personally with the Communicable Disease Officer. It was thought to be unlikely that any parent would keep their child from school because of the fear of HIV transmission.

Confidentiality

There is no legislation on AIDS for school administrators, but co-operative guidelines have been drawn up through the Medical Services and Health Protection Branch, National Health and Welfare, Canada.

Summary

Major issues associated with AIDS in the workplace concern two distinct groups of people: those who are infected, and those who fear to become infected. On the one hand, there is concern over the need to protect the individual's rights to privacy and non-discrimination, and on the other hand, the rights of the public to be protected from a potentially life-threatening disease.

1) For those who are HIV infected, there is the risk of betrayed confidence, which may lead to discrimination; social ostracism; loss of insurance privileges, social benefits, income, housing; and the invasion of privacy.

2) For those who are co-workers with an individual who is HIV seropositive, there may be fears related to the transmission of the disease; feelings of homophobia; anxiety over the wish to change to alternative work opportunities; the need for further or on-going education on AIDS.

3) For the employer, there may be a dichotomy between the duty to protect the rights of the HIV infected employee and those of the employee who is not HIV infected. Decisions have to be made over the question of maintaining confidentiality versus "who needs to know"; the right to "hire or fire"; the onus to provide a safe working place, without betraying the fact that an employee is HIV seropositive; whether to provide AIDS education and training for employees (in whose time and at whose cost?). Certain occupations carry an added responsibility for the employer because of the nature of the work, for example, added burdens of infection control for dentists, health care workers and funeral directors, among others.

4) For schools, where the interests of school boards, employees and parents may come into conflict and be subjected to passionate struggles for control unique to the situation. For school boards, there is a responsibility to provide education to all children, both handicapped and healthy, but at the same time to provide a safe school environment. Some parents may exert pressure on school boards to remove HIV infected persons from a school, while other parents who have an HIV infected child may equally bring pressure to have their child admitted to the school and require the matter to remain strictly confidential. School boards must decide who needs to know the health status of such a child, and monitor the confidentiality required of all who know. Similar issues of confidentiality apply to the teacher or school employee who is HIV infected, and also decisions have to be regularized concerning continued employment (because of the episodic nature of the disease, and there are bouts of acute illness interspersed with periods of well being) and protection of unemployment and retirement benefits.

5) For certain health care professionals there may be added responsibilities, such as the decision whether to disclose privileged information on a patient's HIV status to a spouse who may be ignorant of the facts and in potential danger of death as a result.

In general, the position of the provinces and territories is:

No new AIDS legislation regarding employment/workplace:

New Brunswick, Newfoundland, Prince Edward Island, Quebec, Alberta, Manitoba, Saskatchewan, Northwest Territories, Yukon, British Columbia, Nova Scotia.

Policies being developed:

New Brunswick, Newfoundland, Quebec, Saskatchewan, Northwest Territories, Alberta.

Refusal to work with a PWA:

no case yet tested in Court.

Guidelines for employers:

New Brunswick, Ontario, Manitoba, Yukon (federal), British Columbia, Vancouver City, Nova Scotia, Federal (Manual for small businesses).

AIDS Workplace Consultant:

Alberta

Educational packages for the workplace:

New Brunswick, Newfoundland, Ontario, Alberta, Manitoba, Saskatchewan, British Columbia.

Government policies developed for HIV + health care workers:

Newfoundland, Saskatchewan.

Guidelines for funeral homes:

New Brunswick, Quebec, Alberta, Ontario, Saskatchewan, Yukon, British Columbia, Nova Scotia, Manitoba.

Guidelines for workplace:

New Brunswick, Ontario, Manitoba.

Guidelines for emergency services:

Alberta, Manitoba, Saskatchewan, Northwest Territories, Nova Scotia, Yukon.

Guidelines for schools, day care:

New Brunswick, Newfoundland, Prince Edward Island, Alberta, Saskatchewan, Northwest Territories, Yukon, Nova Scotia, British Columbia, Manitoba, Ontario.

Guidelines for hospitals:

Manitoba, Northwest Territories, Yukon, Nova Scotia, Saskatchewan.

Guidelines for health care workers who are HIV infected:

Newfoundland, Nova Scotia.

Guidelines for food handlers:

Newfoundland.

Guidelines for correctional centres:

Manitoba.

New legislation for confidentiality:

none identified.

Quarantine and Isolation

Federal/Provincial

In February, 1988, the Working Group on Confidentiality, (a sub group of the Federal/Provincial/Territorial Committee on AIDS), recommended all provinces to "have legislation which empowers the public health authority (MOH) to confirm or otherwise restrain persons from irresponsible conduct which constitutes a threat to others".

Alberta

AIDS is subject to provincial law, even though there is no specific AIDS legislation at this time, because the Public Health Act permits people to be isolated for a variety of diseases. There is, however, a strong reluctance to invoke legislation for AIDS except as a last resort.

In the Penal System, some HIV+ prisoners have been placed (for their own protection) in the hospital's ward, apart from the general prisoner population.

British Columbia

In British Columbia new legislation specifies that any Medical Officer of Health can direct someone who is infected with AIDS or is HIV seropositive, and who is either wilfully or carelessly infecting others, to desist, to stop having sex, and/or to remain in isolation in his own home. This law came into force six months ago as part of the Health Act. Enforcement would require taking the person to court. There has been no test case to date.

Manitoba

The Public Health Act legislation could be applied to AIDS in Manitoba, but it would be pursued only after voluntary compliance had failed.

New Brunswick

It may be possible to use provisions under the Health Act to specifically isolate or quarantine an individual with AIDS if all other measures to prevent the spread of disease have been exhausted. There have been no test cases as yet. Much of the legislation relating to communicable disease control is dated. There are no specific regulations relating to HIV infection.

The Board of AIDS New Brunswick has expressed concern to the Minister about restrictions on the food handling business with respect to AIDS.

Newfoundland

The Public Health and Communicable Disease Control Act have been updated in Newfoundland to include AIDS, but there has not been a test case.

Northwest Territories

The Public Health Act has recently been revised and tightened up in view of AIDS.

It does provide for detention of an HIV infected person under certain circumstances, (rather than quarantine).

It is regarded as a health rather than a moral issue.

Nova Scotia

The Public Health legislation in Nova Scotia permits medical health officers to quarantine or isolate persons with communicable diseases if it is deemed necessary. This general legislation could be applied to people with AIDS, but there has not been a test case. Such a step would only be undertaken as a last resort.

Ontario

Ontario has revised its Health Protection and Promotion Act and Health Disciplines Act to incorporate AIDS in the list of designated communicable diseases.

A Medical Officer of Health may order an infected person to "isolate himself and remain in isolation from other persons" (Health Protection and Amendment Act (1983) Section 22 4.c).

Under Section 35, a provincial offences court can order any person who refuses to comply with such an order of the Medical Officer of Health to be taken into custody and detained in hospital for a period of up to four months. The period can be legally extended at the discretion of the Medical Officer of Health by taking the case back to court at four-monthly intervals.

This action has never been taken, but the authority to do so is there. Moreover, detention under the act would be a health, not a criminal issue.

Prince Edward Island

It was thought that existing legislation which has been in effect for years in Prince Edward Island would be sufficient.

Quebec

Quebec has general provincial legislation which applies to sexually transmitted diseases. This legislation permits an infected person to be detained in order to effect a cure. As there is no known cure for AIDS at this time, it may not legally be applied to AIDS; but there has been no test case.

The question of providing legislation to control medically irresponsible behaviour is being discussed.

Saskatchewan

AIDS and HIV infection are named in the Communicable Disease Regulations of the Public Health Act. A Medical Health Officer has the power to isolate an individual who is suffering from a notifiable communicable disease and who poses a justifiable risk to other persons. Such authority is very rarely used, and has not been used for AIDS cases to date.

Yukon

The Medical Officer of Health in the Yukon represents both the Federal and Territorial governments, and has extensive powers of arrest under existing legislation without having to amend the old laws. However, the law states that a person with an infectious disease who refuses treatment can be incarcerated in order to effect a cure. Since there is no known cure for AIDS and there has not been a test case, no one is certain if incarceration of a PWA would stand up in Court.

It was also deemed inconceivable that it would be necessary to arrest someone who is infected with AIDS for this reason. It has never been necessary for other sexually transmitted diseases, and attitudes among the public have always been very co-operative in trying to contain infectious diseases.

Summary

Discussion with representatives from the Provinces and Territories made it very clear that there was wisdom in having legislation in place, but any legislation of this sort would only be invoked as a last resort. The human condition was perceived as calling for compassion and persuasion rather than tough legislative action.

The Working Group on Confidentiality (of the Federal/Provincial/Territorial Committee) recommended that every province should have some legislation to confine or restrain irresponsible conduct which constitutes a threat to others.

Existing legislation thought to be sufficient:

Through	Public Health Act	Manitoba
	Public Health Act	PEI
	Communicable Diseases Act	Saskatchewan
	Public Health Act	Nova Scotia

Changes to legislation under discussion:

Through	Public Health Act	Alberta
	Public Health Act	New Brunswick
	General provincial legislation	Quebec
	Public Health Act	Yukon

Revised legislation to include AIDS:

Through	Public Health Act	BC
	Public Health Act	NWT
	Health Protection/Communicable Diseases Act	Ontario
	Public Health and Communicable Diseases Acts	Newfoundland

Every Province or Territory considered it to be a public health and not a criminal concern, although the opinion that it might be a borderline issue was also expressed.

Groups Created for the Management of AIDS

Federal

The National Advisory Committee on AIDS (NAC-AIDS)

The Federal Centre for AIDS (FCA)

The Federal/Provincial/Territorial Advisory Committee on AIDS, and its sub-committees

National

Some existing societies/associations became significantly involved with AIDS besides their usual activities:

- The Canadian Public Health Association (CPHA)
- The Canadian Haemophilia Association
- The Red Cross

National Community Groups

The Canadian AIDS Society (coalition of community groups)

Alberta

Provincial Advisory Committee on AIDS

Steering Committee on AIDS

Working Groups of the Provincial AIDS Program

Community Groups

AIDS Calgary Awareness Association

AIDS Network of Edmonton Society

Central Alberta AIDS Network

Lethbridge AIDS Council

South Peace AIDS Council

A Co-ordinated Community Response Society of Jasper

British Columbia

Provincial Advisory Committee on AIDS (PAC - AIDS)
Mayor's Task Force, Vancouver City (Recently completed report)
Every hospital has an AIDS Committee

Community Groups

AIDS Vancouver
AIDS Vancouver Island
AIDS Kelowna
PWA's Coalition

Manitoba

Provincial Advisory Committee for AIDS
Interdepartmental Committee for AIDS
Manitoba Education Council on AIDS
Ad Hoc Committee on Provision of Services to Persons With HIV Infection

Community Groups

Winnipeg AIDS Advocacy Council
Winnipeg Gay Community Health Care, Inc.

New Brunswick

Department of Health

Inter-Disciplinary Committee on AIDS
Provincial Advisory Committee on AIDS

Community Groups

- AIDS New Brunswick
- AIDS Committee of St. John Municipaltiy
- Moncton Group for Support Services (no name yet)

Newfoundland

Department of Health

- Provincial Advisory Committee on AIDS
- Health Unit Regional AIDS Public Education Committee (five)
- Provincial AIDS Public Education Working Group

Community Groups

- Newfoundland and Labrador AIDS Committee
- Health Science Centre Support Group for AIDS (being developed)

Northwest Territories

AIDS Co-ordinating Committee

Nova Scotia

Nova Scotia Task Force on AIDS (created to recommend policy for consideration by government).

Community Groups

- Metro Area Committee on AIDS (MACAIDS)
- N.S. PWA Coalition
- Christians Assembled to Respond to AIDS (CARA)

Ontario

Provincial Advisory Committee on AIDS (PACA) (1983)
Ontario Public Education Panel on AIDS (OPEPA) (1985)
Interministerial Working Group on AIDS (1986)

Community Groups

AIDS Committee of Toronto
Toronto PWA Foundation
AIDS Committee of Thunder Bay
AIDS Committee of Windsor
AIDS Committee of London
Hamilton AIDS Network for Dialogue and Support
AIDS Committee of Cambridge, Kitchener, Waterloo and Area
Kingston AIDS Project
AIDS Committee of Ottawa

Prince Edward Island

Provincial Advisory Committee on AIDS

Quebec

Department of Health

Working Group on AIDS

Community Groups

Comité SIDA-AIDE Montréal
Montréal AIDS Resource Committee
Mouvement l'Information et d'Entraide dans la Lutte Contre le SIDA à Québec

Saskatchewan

Provincial Advisory Committee on AIDS

Community Groups

AIDS Saskatoon
AIDS Regina

Yukon

At this time most AIDS issues are dealt with through the Communicable Disease Office or appropriate local authorities.

Summary

Federal:	National Advisory Committee on AIDS (NAC-AIDS) The Federal Centre for AIDS (FCA) The Federal/Provincial/Territorial Advisory Committee on AIDS A wide variety of national groups (identified four)
New Brunswick:	Inter-Disciplinary Committee on AIDS Provincial Advisory Committee on AIDS Three community groups
Newfoundland:	Provincial Advisory Committee on AIDS Five Health Unit Regional AIDS Public Education Committees One community group One community group being developed
PEI:	Provincial Advisory Committee on AIDS

Quebec:	*Working Group on AIDS* Three community groups
Ontario:	Provincial Advisory Committee on AIDS (PACA) Ontario Public Education Panel on AIDS (OPEPA) Interministerial Working Group on AIDS Nine community groups
Alberta:	Provincial Advisory Committee on AIDS Steering Committee on AIDS Working Groups of the Provincial AIDS Program Six community groups
Manitoba:	Provincial Advisory Committee on AIDS Inter-departmental Committee for AIDS Manitoba Education Council on AIDS Ad Hoc Committee on Provision of Services to Persons with HIV Infection Two community groups
Saskatchewan:	Saskatchewan Advisory Committee on AIDS Two community groups
NWT:	AIDS Co-ordinating Committee
Yukon:	Communicable Disease Office or appropriate local authorities deal with AIDS issues.
BC:	Provincial Advisory Committee on AIDS (PAC - AIDS) Four community groups AIDS Committee in every hospital Mayor's Task Force, Vancouver City (recently completed report)
Nova Scotia:	Nova Scotia Task Force on AIDS Two community groups

Resource Centres for AIDS

Federal

The Federal Centre for AIDS has established a central library as a national resource centre for AIDS.

It includes materials on all aspects of AIDS, including health care, legislation and education.

It has requested copies of all provincial publications.

The LCBC Electronic Board is available to the media and its capabilities have recently been expanded. It lists Canadian and US, as well as international statistics on AIDS; carries special notices; lists coming AIDS conferences; and it also makes available the Canada Diseases Weekly Report and the US Morbidity and Mortality Weekly Report.

The Federal Centre for AIDS is taking responsibility for the development of a national Database, and working with the provinces and territories to increase accessibility and use of the existing networks. The Federal/Provincial/Territorial Committee on AIDS recorded that a co-ordinator from each jurisdiction should be identified to achieve this. (February, 1988 meeting).

At the same meeting, the federal government expressed the intention of developing a national hotline with appropriate linkages to the existing provincial hotlines. Funding for this is still being debated. Funding for a proposed national magazine on AIDS is also being discussed. If this is developed, every effort would be made to ensure co-ordination with the education strategies and campaigns underway in the provinces and territories.

The Canadian Public Health Association (CPHA) received a $3.7 million grant from Health and Welfare Canada to establish a 5-year National AIDS Education and Awareness programme in 1986. It operates a computer-based information clearing house that accesses AIDS information on a global level, and handles more than 600 requests a month.

Alberta

The building of a centralized bureaucracy has been avoided.

Additional funding has provided a major collection in the Community and Occupational Health Library, which provides print resources to professionals and the general public. Audio-visual resources have been made available through the Provincial Film Library and the ACCESS (Alberta Educational Communications Corporation).

Lists of names of resource people who have a particular expertise in AIDS have been made deliberately unavailable. This point is being debated at the federal/provincial level because everything is being done to encourage local physicians to provide medical care for people with AIDS.

British Columbia

The Director of STD Control in Vancouver has manuals, textbooks, articles and pamphlets from all over the world. There is a library of sixty videos, some tapes and some posters. It is mostly used by people who drop in casually, and it is open to both the public and professionals.

There is no umbrella agency, only his office.

Manitoba

There is a Central Resource Centre for AIDS run by the Department of Health which keeps pamphlets, posters, films and videos.

Efforts have been made to work with the federal government and other provinces to avoid duplication.

Both the general public and professionals have access.

The Manitoba Health Resource Centre provides information and resources. The AIDS control section of Communicable Disease Control has developed a resource manual. Lists of key people who have expertise in the field of AIDS are available.

New Brunswick

The AIDS New Brunswick Programme Co-ordinator is building a resource centre for AIDS. So far there are twelve binders, six books and some filing cabinets full of materials.

It is being regularly improved and updated, and is available to both the general public and professionals. At present it is frequently used by students who are writing papers, people who are HIV infected, volunteers and professionals.

A list is being compiled of resource persons who have particular expertise in AIDS.

There is no umbrella agency for the dissemination of information.

Newfoundland

There are resource centres for AIDS in the Public Health Units and anyone can borrow from them.

There is no special library for AIDS materials, but they are stored in the office of the provincial epidemiologist and are available to anyone, both the general public and professionals.

There is no national or international list of people who have expertise in AIDS. There are only a few people to draw on locally and they are well known if resource people are needed.

There is no umbrella agency to distribute information.

Northwest Territories

The Department of Health runs a Health Resource Centre.

Print and audiovisual materials are available. AIDS materials are ordered in conjunction with the AIDS programme.

Anyone in the community, both public and professionals, can borrow from it.

Nova Scotia

There is no special library or resource centre for AIDS in Nova Scotia.

Materials and literature are available from MACAIDS and the District Health Units, and some libraries have developed specific AIDS collections. Anyone may borrow from these.

There is no provincially circulated list of personnel with particular expertise in AIDS. Existing information channels, particularly in the medical field, are used to identify the AIDS-related experts.

There is no umbrella agency to distribute information about AIDS.

Ontario

There is a resource centre for AIDS in the Ministry of Health, with materials in seven languages. This is organized through the office of the Ontario Public Education Panel of AIDS (OPEPA), which acts as an umbrella agency for information and materials.

Anyone may borrow from it, both the general public and professional.

There is no list of personnel with particular expertise in AIDS.

There is a list of Speakers who act as a resource group, and the network has information about other people who are actively involved.

Prince Edward Island

There is no central resource centre for AIDS, and no libraries have yet been advised by the government to get together information on AIDS.

There is no official resource list of people who have expertise in AIDS, neither is there an umbrella agency to co-ordinate information on AIDS.

Quebec

Information on AIDS is available through the Health and Social Services network.

There are resource centres for AIDS in each Centre Locaux de Services Communauxtaires (CLSC). The Ministry of Health and Social Services provides them with information, brochures and video materials. They are widely distributed throughout the provinces and available to the general public as well as to professionals.

Young people are encouraged to seek information through their schools.

There is no major library or resource centre specifically for AIDS. No resource list of people who have expertise in AIDS has been developed for general use.

There is no umbrella agency to disseminate information on AIDS.

Saskatchewan

The Department of Health has several AIDS videos available for public use on request.

The library within the Department of Health has several articles and books on AIDS. These resources are added to on an ongoing basis and are co-ordinated by the Provincial AIDS Education and Prevention Co-ordinator.

The local personnel dealing with AIDS are well known. No particular list is kept.

There is no umbrella agency for AIDS information.

Yukon

The Communicable Disease Officer keeps a supply of materials in her office at the Whitehorse General Hospital, and anyone is welcome to borrow, either the general public or professionals. There are films available for teachers and medical professionals. There are also videos from BC, and some of these can be borrowed, free of charge, from a local video store.

One advantage of having the materials in her office is that she is there to answer questions personally if this is needed, or to refer people to other resources.

The names of resource persons with expertise in AIDS are readily available, and there is a close contact with both BC and Alberta.

There is no umbrella agency to deal with AIDS information.

Summary

Nearly all provinces have resource centres for AIDS, some more sophisticated than others, but all believe they are essential and all are readily available to the general public as well as to professionals.

New Brunswick: in the office of the AIDS Programme Co-ordinator. It is used frequently by students, and is being improved and updated.

Newfoundland: in the Public Health Units and Office of Provincial Epidemiologist.

PEI: resource centres still evolving.

Quebec: in Health and Social Services network. Resource centres also in each Centre Locaux de Services Communautaires.

Ontario: major resource centre in the Ministry of Health, Ontario Public Education Panel on AIDS.

Alberta: major Community and Occupational Health library

Manitoba: major Department of Health central resource centre

Saskatchewan: Department of Health has an expanding resource centre

Yukon: in the office of the Communicable Disease office

NWT: government Health Resource Centre

BC: major centre in the office of the Director of STD Control.

NS: District Health Offices and at MACAIDS.

Umbrella Agency:

Ontario Public Education Panel on AIDS acts as an umbrella agency. No others were identified.

List of resource persons:

New Brunswick: being compiled

Newfoundland: local names known

PEI: local names known

Ontario: list of Speakers. Local names known. Lists generally avoided in order not to create a sense of "special treatment" around AIDS.

Alberta: List of Speakers. Local names known. List consciously avoided in order to reinforce involvement of general physicians with AIDS

Manitoba: Lists kept of resource people on national, international and provincial levels

Saskatchewan: local names known

Yukon: local names known, close contact with BC and Alberta

NWT: local names known

BC: provincial, national and international lists on hand.

Nova Scotia: existing channels of information utilized (no special list).

Quebec: no list for general use.

Research

National

A number of recommendations for the direction of Canadian AIDS-related research and studies were itemized in the Royal Society of Canada Report, "AIDS: A Perspective for Canadians", released April 27, 1988.

They were:

Public Health Education

Box 33, p. 20 - "We recommend studies on the use and meaning of education in relation to the changing sexual and social behaviour among three sectors of our society: people who are HIV-infected, people who are at risk of becoming HIV-infected,and people who work with these two groups".

Box 34, p. 20 - "We recommend studies of how institutions can best achieve their goals of promoting behavioural change in those members of society who are HIV-infected or who are at risk of becoming HIV-infected. Such institutions include among others, correctional institutions, educational institutions, and hospitals and other health-care centres".

Biomedical Research

Box 36, p. 22 - "We recommend that clinical trials of preventive and therapeutic measures be administered with full disclosure of foreseeable risks and benefits, informed consent, and approval from an institutional ethics or human experimentation committee. We seriously question the ethics of using volunteers from the military, children, or the inmates of custodial institutions".

Box 38, p. 22 - "We recommend the establishment of a federally funded resource group, analagous to the clinical trials group of the National Cancer Institute of Canada, to plan and co-ordinate both publicly funded and industry-sponsored HIV-related clinical trails".

Social Science Research

Box 39, p. 23 - "We recommend that the Social Sciences and Humanities Research Council (SSHRC) establish studies of sexual behaviour to assist in the design of education and public health programmes and to establish a database of sexual knowledge, attitudes and practices among Canadians".

Box 40, p. 23 - "We recommend societal and anthropological studies of the relationship between HIV-infected persons and those who interact with them, in order to understand the dynamics of population behaviour, the course of discriminatory behaviour and change, and the basis on which information changes values, attitudes and behaviour".

Box 41, p. 24 - "We recommend studies on the effectiveness of voluntary agencies in conveying accurate and change-inducing information and support to sub-groups engaged in activities within or outside the law, to those who may not be unable to read or hear, and to those who may not be responsible for their own behaviour such as the mentally handicapped. The scope and methods of funding for such agencies will also have to be determined".

Box 42, p. 24 - "We recommend research to determine the means by which high-risk groups, such as injection drug-users and other operating outside the norm or laws of society, may be most effectively contacted and influenced".

Box 43, p. 25 - "We recommend a large multiwave survey of the adult and adolescent Canadian population. This survey would provide currently lacking information about sexual practices, ideas and feelings about AIDS, patterns of social ties and behaviour relevant to the spread of sexual diseases, trust in various sources of information, and other factors bearing on the future spread of HIV infection and means of prevention. These data will be useful for both network analysis and epidemiological purposes".

Multidisciplinary Research

Box 44, p. 25 - "We recommend that the Medical Research Council, the Social Science and Humanities Research Council, and the National Health and Research Development programme use proactive dedicated AIDS committees to promote and support HIV-related research in their respective fields".

Box 45, p. 25 - "We recommend that a national research committee be formed to co-ordinate the AIDS-related research efforts of the Medical Research Council, the Social Science and Humanities Research Council, and the National Health and Research Development Programme and perhaps to co-ordinate other research problems that may transcend their traditional mandates. For example, this committee could be set up under the aegis of the Royal Society of Canada".

Box 46, p. 26 - "We recommend that group programme be established in which personnel with expertise in many different aspects of AIDS-related research can pool their talents to undertake research that is highly cost-effective".

Box 47, p. 26 - "We recommend the development of four multidisciplinary research units that combine the disciplines of clinical epidemiology, public health, economics, and other social sciences, and the creation of one unit for health policy research".

The Royal Society of Canada report gives a detailed breakdown of funding which has been allocated to AIDS research through Federal, Provincial and private sources on pages 26-28.

Of Provincial funding, it says, (p. 27)

"During 1986-87, five provincial government finding agencies contributed over $2.08 million to AIDS and HIV research. Of the total allocated in 1986/87 by all (federal., provincial and other), the Ontario Ministry of Health accounted for 37%, partly because of a large one-time establishment grant. The Alberta Heritage Foundation for Medical Research, the British Columbia Health Care Research Foundation and the Manitoba Health Research Council together contributed 2%. Quebec allocated $250,000 through the Fonds de la recherche en sante du Quebec. In 1987/88 these provincial agencies contributed less than 9% of the approximately $4.26 million spent".

Of future funding requirements for AIDS research it says, (p. 27)

"AIDS and HIV research in Canada has not been commensurate with the magnitude and urgency of the problem or with public expectations. It is unlikely that this situation will change significantly in the absence of proactive initiatives by government and other agencies. Chronic underfunding of scientific research has led to a shortage of human resources. . . . Provincial governments differ greatly in the extent to which they support health research and in the mechanisms they use for supporting it. This applies equally to AIDS-related research. It is difficult, therefore, to recommend a general policy for such funding.

Box 48, p. 28 - "Because of the importance of developing a co-ordinated approach to research finding, were recommend a meeting of federal and provincial ministers be convened as early as possible to discuss appropriate mechanisms for sharing the responsibility of supporting AIDS-related research".

Another major paper urging the necessity for research is the Somerville and Gilmore report "HIV Antibody Testing in Canada" for the McGill Centre for Medicine, Ethics and Law. In the Preamble, page 4 it states, "In preparing this report, it has become apparent to us that there is a great need for research on all aspects of HIV antibody testing in Canada. There is an especially urgent need for research on:

1) the accuracy of the information HIV antibody testing provides;
2) the use of this test, and of the information it provides;
3) the effects of this test on behaviour relating to HIV transmission; and
4) the legal implications of this test. Until this research is done, great caution must be exercised in implementing HIV antibody testing or screening in Canada".

Alberta

There has been little funding of AIDS-related projects, either basic or applied, from Alberta sources, although several studies supported by Federal funding are underway within the province.

The document produced by the Community and Occupational Health Department, "Education and Caring, Alberta's Programme for AIDS" (October 1987) reports:

"Assessment of educational and risk reduction efforts is badly needed. Although world-wide efforts at prevention of HIV infection through education are taking place, there is little literature describing the effectiveness of these programmes. Further, as the use in Canada of media to transmit health education messages is just beginning there is much to be learned regarding our public's response to such efforts". (Goal 8, p. 28, Background, para 2).

British Columbia

There is a great deal of research being done. One of the best known is the study of the culture of the AIDS virus and the building of new laboratory facilities to do this.

Manitoba

There is no provincial government funding to support AIDS research at this time.

New Brunswick

There was reported to be no provincial government research on AIDS taking place in New Brunswick at this time.

Newfoundland

There is no provincial funding for research, and nothing has been targeted, but the province does participate in national clinical drug trials.

Northwest Territories

There is a full-time Research Worker who was hired six months ago, and is now working in the Office of the Medical Officer of Health, and who will primarily be doing evaluation of the AIDS programme, as well as providing up-to-date information for it.

Nova Scotia

There is no government funded provincial research on AIDS at this time.

The Victoria General Hospital is participating in the nation-wide "open trial" of AZT drug therapy, with about 30 people with AIDS.

Dr. Ken Rozee of the VGH/Dalhousie Medical School is doing epidemiological research on HIV prevalence as part of a nation wide effort.

Ontario

The Ministry of Health has spent more than $2,750,000 on AIDS research projects in the province of Ontario to date.

Substantial grants have been awarded to:

- the University of Toronto to establish the province's first HIV isolation facility (May, 1987)
- The University of Toronto, for a comprehensive epidemiological study directed by Dr. Randall Coates
- The Toronto Hospital for Sick Children for diagnostic screening studies
- The Victorian Order of Nurses, to research the level of knowledge and concerns about AIDS among the 2,500 visiting nurses of the Order, with a view to developing an AIDS information programme for visiting nurses.

The government has also provided annual funding and one-time capital grants to operate FACSan analyzers to perform T4 cell counts on patients infected with the AIDS virus at:

- St. Michael's Hospital
- Sunnybrook Medical Hospital
- The Hospital for Sick Children

There is still money available to fund AIDS research, but not many high quality projects have been brought forward.

Funding is being targeted as applications are made, and there is a committee which decides on research policies.

Prince Edward Island

There is no formal provincial research on AIDS taking place in the province.

Quebec

There has been provincial support for a wide range of research activities. Special interests have included AIDS surveillance, and studies about haemophiliacs and Haitian immigrants with relevance to the AIDS crisis.

It is expected that the Working Group on AIDS will be including recommendations for research when it makes its presentation to the Minister in August 1988.

Saskatchewan

The virology/immunology group at the University of Saskatchewan is carrying out research with regards to a model for HIV virus infection. This is funded by NHRDP. In addition the same group is conducting contract research on a possible HIV antigen test.

Yukon

There is no Territorial government funding for AIDS research.

Summary

Most provinces or territories reported that there was either very little or no research being done through provincial funding.

No provincially funded research on AIDS

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Research funded by Province/Territory underway

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Report to Chairman, Nova Scotia Task Force on AIDS: Visit to England, Australia and New Zealand

by

Louis Vagianos

April 1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

Report to Nova Scotia Task Force on AIDS:
Visit to England, Australia and New Zealand

Introduction

This brief report of findings gathered during a trip to England, Australia and New Zealand does not include or incorporate information found in the public and confidential documentation which was amassed and is now being reviewed. The intent is to try to provide a sense of the knowledge gained from discussions with a wide range of staff as to what is going on out there.

Purpose of Trip

To visit as many AIDS Centers as could be fitted reasonably within the general itinerary already planned for a world trip in order to: gather reference materials for possible use by the N.S. Task Force on AIDS; identify strategies in use within the jurisdictions visited; and explore any lessons learned from their experiences.

In all (excluding travel), 14 days (5 in London; 1 in Edinburgh; 2 in Melbourne; 1 in Canberra; 2 in Sydney; 1 in Auckland, and 2 in Wellington) were spent on the project.

Places Visited

London:	Department of Health and Social Security Public Lab Health and Education Authority (631-0930) National AIDS Trust (388-1182) AIDS Education Project (289-5637) Terrence Higgins Trust (831-0330)
Edinburgh:	Scottish Health Education Group (447-0044) Health Education Centre (Woburn House)
Melbourne:	Victorian AIDS Council (417-1759) Gay Mens Health Centre Communicable Disease Centre (602-4900)
Canberra:	National Department of Health (897011) Department of Community Services and Health Drug Dependency Unit
Sydney:	Department of Health (New South Wales) (217-6666) Department of Education, Schools Directorate AIDS Council of New South Wales
Auckland:	New Zealand AIDS Foundation
Wellington:	National Department of Health Health Promotion Program (727627)

Two Caveats

1. The trip proved useful for three reasons:
    - All three countries are significantly ahead of Canada and Nova Scotia in dealing with AIDS, so that the meetings were particularly informative; moreover, the meetings fell at an opportune time, because many of the strategies which had been in use during the past few years were being (or had been) refined or revised on the basis of experience and the material prepared for future "campaigns" which was available reflected the changes.
    - An enormous quantity and wide range of extraordinary, extremely detailed, and particularly relevant documentation was accumulated for use by the NSTFA. It focussed on four areas:
        1) educational teaching material
        2) public information campaigns
        3) government surveys, statistics, and strategies (including confidential reports)
        4) materials prepared by the voluntary sector.
    - A network of contacts was established through which Nova Scotia can continue to profit and to which it is *expected* to contribute.
2. Given that time was a major factor and a suitable and effective international medical and research report network for AIDS already existed, little effort was made to accumulate information regarding medical research or to talk to researchers.

General Observations

There was general agreement on the following issues, although there was variation as to how to meet specific goals which emerged as a result:

1. AIDS is a world-wide phenomenon that has not yet peaked and is unlikely to disappear quickly or easily. For this reason, an international effort will be needed, should be coordinated by the World Health Organization, and must be supported financially by all nations able to do so.
2. Every jurisdiction should enact legislation which will ensure appropriate funding for the fight against AIDS. Funding should be based on three to five year cycles to permit planning to evolve in an orderly fashion. Year-to-year funding is inefficient, causes problems, and leads to incoherent programs.
3. A permanent agency which is free of direct government control and involvement is necessary on both the federal and local (state, province, etc.) levels to coordinate the day-to-day activities needed to initiate and reinforce whatever measures are put in place to combat AIDS. Such agencies are already in place in the countries visited and are considered to have been both successful and effective. Wherever possible, the agencies must have as much local representation and involvement as possible.
4. The principal effort to control AIDS must be positive (up-beat) and should be based on the knowledge that prevention is not difficult. Safe sex is both possible and desirable. What

must be accomplished is a "safer sex" program; therefore what is necessary is a radical change in social behaviour.

5. Every nation (province) should have efficient systems in place for screening 100% of blood and organ donations.

6. Monitoring and surveillance of the AIDS phenomenon is essential, but all testing, independent of why it is being done or for whom:

   - should be voluntary (A particular problem which must be addressed involves employees of airlines where compulsory screening of employees may be necessary.)
   - must be anonymous
   - has to be absolutely confidential (Determination that an individual has AIDS or has contracted the HI virus may trigger a different set of rules. But any set of rules used to deal with PWAs must place the good of the patient on the same basis as that of society in general.)

7. Where needed, legislation should ensure PWAs and HIV + persons:

   - are assured some form of insurance
   - are protected against job discrimination
   - are not penalized in immigration procedures

8. Specific minority groups require imaginative approaches and special messages. For example, bi-sexual activity is culturally acceptable for ethnic groups such as Turks and the Maoris. In the case of prostitutes, legislation setting standards of operation and specialized information programs for improving specific knowledge on AIDS have proven effective. In the case of ethnic groups and bi-sexuals, a concerted effort to involve women, either through planned parenthood groups or other health organizations is being introduced.

9. The need to include the handicapped (blind, deaf, etc.) in public education campaigns should not be ignored. Within this context, it may also be useful to add prison inmates and incarcerated mentally handicapped patients.

10. At present, the major encroachment of AIDS into the heterosexual community has been through intravenous drug users. To combat this trend, needle exchange and educational programs are necessary.

11. A concerted effort is needed to introduce curriculum changes in public school systems which will introduce a formal requirement for an *integrated* health education component to deal with all STDs. In the long-term, education of students is the best hope for controlling the problem.

12. The key to any successful AIDS response is three-fold:

    a) enlightened government support

    b) appropriate involvement from the voluntary sector

    c) a good, direct, and permanent public education campaign must be introduced.

    These three points were the single most important themes emerging from the discussions. Some elaboration is in order.

a) Enlightened Government Support

There was general agreement that legislative and financial support is important at all levels of government. But, equally important, there is a need for governments to be seen as providing moral leadership too. In general, moral leadership was defined to mean that support transcended political partisanship or parochial feelings. At the same time, it was acknowledged that governments could not become advocates of specific "sexual policies" (e.g. condoning the use of condoms or monogamy rather than a variety of partners, etc.). For this reason, all of the countries visited placed a premium on providing a quasi-independent agency (e.g. U.K.'s Health and Education Authority; Australia's Victorian AIDS Council, or New South Wales AIDS Education Bureau; New Zealand's AIDS Foundation) through which government could work to create systems for: helping people with AIDS, developing public education campaigns; disseminating information; and coordinating national and local responses.

b) Appropriate Voluntary Sector Involvement

There was a genuine belief that the real human resources and support costs of AIDS have not yet surfaced. But one fact has become clear: traditional methods for dealing with patients and existing resources will not be adequate. Hospitals are not equipped to cope and costs (both human and financial) will be prohibitive, if an effort is not made to deal with PWAs differently. This means hard choices need to be made and more imagination is required, in light of competing societal needs and ever diminishing resources. What is already obvious is that much more personal care, counselling, and attention will be needed to minister to victims and a different infrastructure (e.g. hospices, special clinics, counsellors, nurses, etc.) must be considered. The public sector which shows both the inclination (including the necessary compassion) and potential for meeting the new challenges is the voluntary sector (see New Zealand model which is particularly effective and the San Francisco model which has served as everyone's prototype.) However, for such voluntary organizations to be successful, community participation and local support must be marshalled. This means volunteer agencies must be carefully financed. Most countries have opted for some form of initial "seed money" and a "matching fund" arrangement. The volunteer agencies should also be closely linked to and involved in the planning process and the activities of the community they serve. Additionally, they must be supported by external agencies in a manner that permits freedom to be innovative. This means funding and organizational mechanisms which provide help must avoid politics and minimize bureaucracy.

c) A Direct and Permanent Public Education Campaign

The consensus was that there must be a direct and permanent public education campaign. Further, most effective, permanent public education campaigns evolve from appropriate market research (Stress was placed on the fact that although similarities exist among markets, markets also exhibit unique characteristics.) The public information campaign must also evolve in stages.

Stage 1 involves a massive general public information campaign which seeks to raise public awareness of the problem. This campaign has generally been national and paid for by the federal government. (Stage 1 never ceases; it remains in place permanently with reduced dosages. The reason? The public needs continuing reminders, reinforcement and up-to-date information which serves as a basis for the work to be done in the other stages.

Stage 2 involves the targetting of specific general audiences who are easy to reach and should be willing and enthusiastic participants in the dissemination process. This audience includes educators, medical professionals (doctors, nurses, dentists, pharmacists, etc.), and civil servants (government employees, policemen, firemen, etc.).

Stage 3 moves to still more specific audiences. They include parents, public school children, unions, other employees, professional groups (insurance adjusters, salesmen, etc.), the handicapped.

Stage 4 is even more specific: groups associated with high risk activity (e.g., drug users, prostitutes, bi-sexuals, prison inmates, etc.)

Stages 2, 3, and 4 can (and probably should) be done concurrently, but care must be taken to develop the right "packages" and appropriate "delivery mechanisms" for each group. Although similarities will exist in the message to be developed and delivered, the intent involved will vary among the groups and so will the medium. For example, in group 2, one of the intents is to train a "cadre" of people who will be able to carry the message to constituencies. Unlike some of the other groups, group 2 may simply need proper manuals, a video, and some modest instruction. (It may be useful to note that stress was continually placed in the area of preparation of materials. Specifically, wherever and whenever possible, it was suggested "peers" be used to help prepare the material and be involved in the instruction.)

Finally, no public education campaign starts in a vacuum. In most developed countries the population begins at a reasonably high knowledge level concerning AIDS. The problem is that few individuals believe the evidence of risk concerns them. As a result, there has been little evidence of change in behaviour to date and this is the challenge that must be faced. Throughout the discussions, it became very clear that two factors have been grossly underestimated: the extent of the behaviour change that must be addressed; and the amount of time which is necessary to effect such changes.

The Message

In terms of the general message that was to underpin the public information campaign there seemed to be a great deal of unanimity. In general it was felt that the message should be direct and as explicit as the culture would permit. The message should also avoid seeming to be a product of a faceless bureaucracy and should conjure up pictures that are authoritative but friendly. Moreover, the message should focus on eight points:

1. AIDS is a personal threat
2. AIDS is preventable
3. AIDS will require a change in behaviour, but people can manage the change in behaviour with modest hardship
4. SAFE SEX is the key to the new change in behaviour and it is not and need not be second best (individuals can be inventive)
5. Drugs are dangerous, should be avoided, and are not a substitute for the real world

6. When travelling abroad, travellers should remain vigilant as the risks may be even worse than those at home
7. There are a lot of people ready, willing and able to help anyone needing support
8. Self-esteem must be the primary aim.

It was also suggested that where young adults were concerned, market research supported the need for an approach which emphasized three aspects:

1. Since young adults seem to know the basic facts involving AIDS, what is needed is continuous reassurance that these facts have not changed.
2. Young adults needed guidance as to how to talk about AIDS when meeting someone with whom they wished to have sex.
3. Young adults needed advice as to how to deal with promiscuity (infidelity) which had already occurred.

Media and Other External Groups

Gain the assistance of the media from the outset and seek help from as many community groups as possible (churches, YMCA, YWCA, Boy Scouts, Girl Guides, etc.) in developing the message and in distributing it. Involve everyone throughout the campaign. Develop a multi-media campaign which is continuous, multi-facet and easily identifiable, and a part of normal activities (see Australian Safe-sex campaign which includes messages on milk containers among other media).

Other Observations Underscored

Women:

Throughout the trip (particularly Australia and New Zealand), it was suggested that women would have to take charge to minimize the risk of AIDS spreading into the heterosexual community. Planned parenthood groups were given as ideal community mechanisms for reaching women. Although some concern was expressed that this might be an unfair burden to place on women, they suggested market research exists to indicate women would be able and willing to undertake the task.

Target Groups:

"Target groups" are best picked from good market research which was clear about why it was commissioned. Once a "target group" is selected and a program is developed, the program should be pursued until it brings results. But all programs should work within limited and clear objectives, fixed budgets, specific time frames, and, where possible, use individuals chosen from the group being targetted to help in the project. More important, when you have to develop a program, pick as "guinea pigs" individuals or groups who are willing to cooperate. As you gain experience, you can refine procedures and move out to the community at large.

Counselling:

Counselling is one of the best and single most important ways to help PWAs, but one must be careful in selecting counsellors, particularly if they lack genuine language skills (where this applies) or have not come out of the culture.

Workshops:

Workshops have proven the most effective way to deal with police, prisons, housing, civil servants, community services, and public education in the U.K., Australia, and New Zealand. Such workshops are generally for two days and the material was prepared in consultation with staff from the groups involved. Teaching was done, if possible, by local staff after a brief training period.

Law:

There was a general view in Australia and New Zealand that to have truly successful societal prevention programs to combat AIDS certain activities had to be decriminalized (e.g. gay activity, needle exchanges, certain drug uses).

AIDS: Some Positive Aspects

As a result of AIDS a variety of major problems which have been ignored or improperly addressed are being reviewed:

1. infection control guidelines
2. post-mortem procedures
3. methods for disposal of contaminated wastes
4. proper use of health-care facilities and systems, including an assessment of holistic medicine
5. the role of palliative care in dealing with terminal illness

Put another way, society is being forced to return to "basics" in assessing both medical requirements and societal responses.

Louis Vagianos

April 7, 1988

Report to Chairman, Nova Scotia Task Force on AIDS:

Visit to San Francisco and Vancouver

June 1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

Report to Nova Scotia Task Force on AIDS:
Visit to San Francisco and Vancouver

Introduction

The Nova Scotia Task Force on AIDS was established on November 6, 1987. It subsequently divided into three Working Groups. The mandate of Working Group III was to examine the issue of AIDS in relation to the provision of health and other types of care. In addition to the commissioning of research papers, receiving public and private presentations, and studying reports and programs dealing with AIDS in other jurisdictions, it was considered desirable to enable Task Force members to visit certain areas where the impact on health and related care services caused by AIDS has been widely felt. With the assistance of federal monies, two members of Working Group III were able to speak firsthand with care and service providers from both the public and private sectors, as well as recipients of these services, and to hear from both perspectives the strengths and shortcomings of current services.

San Francisco Visit

June 7, 1988: Visit to the AIDS Day Care on 333 Valencia Street in San Francisco

We met with a Miss Sharon Fluet, Volunteer Coordinator for that organization. During our time with her, we also met the Project Director, Jeffrey Sterman. He is the only paid employee attached to this group. The Board of this group was formed in June of 1987. Currently, they have an administrative office only and are not expecting to provide service for another eight to nine months. The model of service that they have chosen is that of the Adult Day Care (see Annex A) for Seniors and, as such, will be licensed by that authority.

The AIDS Day Care intends to start with 25 clients, adding five a month until they reach a maximum of 75. They will have nurses, social workers, activity therapists, and transportation aids as part of the provision of services in their program. They intend to gear the program to the needs of the AIDS patient. As such, they will also have an infusion provision at a reduced rate. We were told that there would be stringent admission guidelines to this particular program; however, they were not made available to us at that time. The location of the Day Care facility has not yet been determined. We did ask if there were problems experienced by individuals with AIDS in securing adequate housing. To this question, we were informed that the State of California now recognizes AIDS as a disability so individuals are eligible for housing, etc. Miss Fluet did, however, indicate the state does not recognize ARC patients, so the real housing problems lie with that group.

Funding

The AIDS Day Care is to be licensed by the state as a private, nonprofit organization. Start-up monies have been received from a number of different foundations. Presently, they are applying for funds from the United Way and also the city is applying for federal monies for this group. It was reinforced at this time that there is a heavy reliance on volunteers and this will continue. We did ask whether there would be an actual per diem charge to the client when the Day Care Program is opened. To this we were told that the per diem to the client, if the client were able to be private paying, would range between $75.00 and $100.00 per day. They will be receiving, for individuals on assistance, a MEDI-CAL payment in the amount of $40.00 per day per client. However, they are applying for an increase in this per diem rate through MEDI-CAL.

In addition to the provision of nursing care services, transportation assistance, and individual and group activity, there will also be the provision of meals while the individuals attend the Day Care. The meals will be provided by a group by the name of "Open Hand." This program is coordinated by an individual by the name of Ruth Brinker. It is a volunteer agency and currently brings meals to individuals living at home. The individuals attending the Day Care will be provided with one meal a day, plus two snacks, once it is open.

Throughout our discussions with Sharon Fluet, the one area of tremendous need which was emphasized was the care to the individual with dementia. As Miss Fluet indicated, these individuals are particularly difficult to care for at home. It is difficult to get and maintain caregivers in homes because of added care requirements. There will be a special program for individuals suffering from dementia, and this program is expected to come on stream approximately six months after the opening of the Day Care Centre. Another area of concern expressed by Miss Fluet are those clients who are I.V. drug abusers and who suffer from AIDS. We were told that these individuals are not eligible for entrance into the gamut of services provided to individuals suffering from AIDS. The only program offering assistance to these individuals is the Catholic Social Services Program. This program provides assistance to I.V. drug abusers and alcoholics who are left on their own. We were told that all other groups and agencies require individuals to abstain from I.V. drug abuse or abuse of alcohol in order to be eligible for any kind of assistance in their program.

We were also told during our conversation with Miss Fluet that in the San Francisco area, people prefer the Home Care Model to the Day Care model. However, it has been found that there are too many people requiring home care, and it is simply too costly.

At the end of our discussions with the individuals from AIDS Day Care, we were informed of several other groups or agencies providing services to individuals with AIDS. We learned of what is called the "Coming Home Hospice." This hospice provides care to individuals who basically are coming home to die. This hospice is a part of the Visiting Nurses group. A second service is called "Ellipse," and we were told that this is the only convalescent hospital in California. Lastly, we were given the names of three gay newspapers which, according to Miss Fluet, give a lot of valuable information. These are as follows: one is called *The Sentinel*; a second newspaper is called *The Bay Area Report*; and the third is called *Coming Up*.

In summary, we found an organization called "AIDS Day Care," consisting of a paid Project Director and a full-time volunteer Coordinator, accommodated in a fairly large office space with computer backup; yet, despite being formed in June of 1987, they do not project a client caseload or provision of care to a client for another eight to nine months. Further, it appears this will be a limited day care operation with a relatively high cost of service delivery and a lack of coordination with other AIDS groups or agencies.

June 8, 1988 - Visit to San Francisco AIDS Foundation

We met with Mr. Mitch Bart, who is the Deputy Director of the San Francisco AIDS Foundation, along with a number of other representatives from other jurisdictions in the United States, Spain, and England. We learned from Mr. Bart that the San Francisco AIDS Foundation's annual operating budget rose from $80,000.00 in 1983 to $6,000,000.00 in 1988. They currently have 87 paid staff and 350 - 400 volunteers, who average three hours' volunteer time per week.

We were informed that the primary role of the San Francisco AIDS Foundation is that of education. Part of their educational package is the provision of an AIDS Hotline Service, which is a volunteer staffed information and referral service, is toll free in northern California, and is in daily operation. We were told that this is not a crisis hotline. It is not for crisis intervention. It is educational, not client-service oriented. Further, we were told the hotline is offered in English and Spanish; and for the last two years, there seems to be a prevalence of heterosexuals calling the hotline, as prior to that time it was primarily gay males calling. Many of these calls were an expression of fear and anxiety after sexual contact, particularly after a one-night stand.

The Foundation offers an AIDS Education Training Program. This is for individuals from around the world who require training in AIDS education, and it is scheduled two months in advance. Another part of the Educational Program provided through the Foundation is the Educational Assistance Program, whereby help is given to minority groups to develop their own educational program. In addition to assisting minority groups with the development of educational programs, the Foundation also mobilizes other community groups to assist with their educational efforts. The Foundation uses market research to assist with the development of educational campaigns geared to target groups. An example of this would be the recently launched "Bleach Man Campaign," which was developed to reach I.V. drug user groups regarding the sharing of needles. We were told that each year there is a focus on a particular aspect of the campaign message to a special or target group. We were told as well that there are specific promotional events during which staff, etc., go to an area where target groups congregate and give out promos; for example, bottles of bleach, T-shirts with "Bleach Man" on them, etc. It was further noted by Mr. Bart that almost all radio and TV channels have an assigned reporter and producer to cover AIDS information and events. Further to the education division, there is a marketing division whereby educational materials are sold to public health departments and other AIDS agencies. The Foundation also sells and markets for other groups. To this end, they made $2,000,000.00 last year. They soon will be initiating a consulting program; and this, again, will be viewed as a revenue generating program.

A second service provided by the Foundation is a Client-Services Department. We were told that this is complementary to the Shanti Project which will be discussed later. The Client-Services Department of the Foundation consists of seven professional social workers who are used to access housing, social services, and medical services for clients with AIDS. These social workers also serve ARC patients. These social workers perform limited case management roles. The case management function is given only at the time the client actually needs it. The AIDS Foundation provides two social workers to ensure people have housing -- short-term housing either in a hotel, or they have an eight-bed flat with a two-week maximum length of stay. Currently, they have six to seven individuals residing in hotels per week, and the eight- bed flat is always full.

Another client service provided through the Foundation is that of a food bank. Monies, etc., are collected to provide groceries to clients. Volunteers assist by collecting and delivering necessary food to the clients. U.S. Government surplus foods are also donated. Four hundred people per week are seen at the food bank. When asked what the most pressing issue over the last year has been, we were informed that housing has caused the greatest problem, over the last six months in particular.

It should be noted at this juncture as well that individuals who have an HIV-positive status are not eligible for the services of the Foundation.

Another function of the AIDS Foundation is that of advocacy. Through their Public Policy Section, the Foundation is called upon to provide testimony, to answer questions, and to work with legislators. The Foundation works to ensure that legislation is based on medical facts, provides a humane response to problems by AIDS, and is cost effective.

Lastly, is the fund-raising function of the Foundation. This Section consists of four full-time paid staff members whose job it is to develop fund-raising schemes for the Foundation.

Visiting Nurses and Hospice

While in San Francisco, we contacted the Visiting Nurses and Hospice to see if we could speak with the group and find out what provision of services they are providing to individuals with AIDS. I spoke with Mrs. Hunter Pearson, who is the Coordinator of the program; and as we had not made a prior appointment, she was unable to accept our visit on the day that we were available to meet. Mrs. Hunter Pearson, however, did indicate that if any information was desired by our Task Force, she could be contacted by mail at Fox Plaza, 1390 Market Street, Suite 510, San Francisco 94102.

Shanti Project

Our last afternoon in San Francisco was spent visiting the Shanti Project. We spoke with Greg Day, who is the Public Education Director of the Shanti Project. Further on, you will find an overview of the Shanti Project (see Annex B); however, I will just briefly outline their program and note any additional information provided during our session.

The Shanti Project was founded in 1974 by Dr. Charles Garfield and was designed to provide support services for persons with life-threatening illnesses and their loved ones. The project in 1983 limited its program to serve only persons with AIDS and their loved ones in San Francisco. Their current budget for 1988 is 3.2 million dollars. They have 70 paid staff members and 600 volunteers serving over 4,500 people with AIDS and their loved ones annually. According to the Public Education Director, Mr. Greg Day, 96 percent of those individuals diagnosed with AIDS in San Francisco are gay or bisexual men.

As noted in the Shanti overview provided, the Shanti Program includes the following: emotional support, practical support, a residence program, counselling at San Francisco General Hospital, information and referral, and public education. The Residence Program, as outlined in the overview, is designed for individuals without income. These individuals are usually on social assistance. Rent is limited to one- quarter of the individual's monthly income. A total of 95 people with AIDS and severe ARC are served annually. The progrm has twelve multi-person apartment units with a total of 47 residents in an independent living environment. It is not a licensed program. It is designed for independent living on the Cooperative Living Model.

Counselling at San Francisco General Hospital is provided by eight paid staff members of the Shanti Project. The counselling services in the hospital are limited to Ward 5A, but also extend to peer counselling for outpatients as well.

Comments and Observations on the Visit to San Francisco

Despite the media attention provided to us in Nova Scotia on the AIDS problem in San Francisco, throughout our stay it was difficult to grasp the seriousness of the problem because it was basically invisible to the visitor in the city. We literally searched in every area of the city for signs of the AIDS problem in that city; however, we only found one restaurant which had handouts of an upcoming gay/lesbian parade. We noted that San Francisco is a very segregated city. It is divided into districts, and ethnic groups appeared to be assigned to certain districts and tend to stay in them. An example of this is the Oakland area across the bay where people are predominately black. We spoke with several individuals from the public at large and incorporated some questions about the AIDS problem in San Francisco to hear their comments. Basically, the impression that was left with us was that this was not a problem for the public at large; it is still very restricted to the gay population and those individuals who are IV drug abusers. It appeared, from our conversations with the various groups and agencies, that the various levels of government have basically brokered out to self-interest groups, self-help groups, and nonprofit organizations the responsibility for the provision of care and services to individuals suffering from AIDS. It also would appear, from the information obtained and from the various criteria developed by each group, that accessing care and services for individuals with AIDS must of necessity be, at the least, difficult.

Vancouver Visit

Vancouver PWA Coalition

We met with representatives of the Vancouver PWA Coalition on June 9 in Vancouver. We were received by Jackie, who, we were informed, was the only member of the Coalition who is female and who is not a PWA. She introduced us to Kevin Brown, who is one of the founding members of the Coalition, which was formed in the spring of 1986. He informed us that the reason the Coalition was formed was the feeling of the PWAs that, "They (AIDS Vancouver) would help you to die, but there was no one to help you to live."

The PWA Coalition consists of 100 male members. All are PWAs or PWARC. The main reason for the existence of the Coalition is:

1. The desire of PWAs to have access to experimental drugs; and
2. The advocacy role for PWAs.

We were told that initially the PWA Coalition lobbied with Public Health for a viral lab, as this was necessary to do viral research to develop and monitor experimental drugs. We were further told the lab has since been built; but, to Mr. Brown's knowledge, AIDS drug research is not going on.

The Coalition is based on a self-help, self-care model. It is their belief that by becoming actively involved they tend to live longer, although Mr. Brown stated this has not been statistically proven. "It just seems to be a sense." The Coalition broke off from AIDS Vancouver in 1986, as they believe AIDS Vancouver was not acting as advocates for PWAs. Funds from AIDS Vancouver are made available for emergency housing, etc., but not available for PWAs to explore health options. The Coalition will fund PWAs up to a thousand dollars per year in $200 installments to explore health options, go to workshops, etc. The Coalition has nine Board members – all PWAs. They have four standing committees. These are Program, Finance, Personnel, and Advocacy.

As noted earlier, the Coalition has 100 male members. They have not had a female member to date, although they indicated they would welcome females. The Coalition has a policy whereby new members wishing to join the Coalition must agree to have a check made on their diagnosis, as the Coalition has had people try to join who are not PWAs. The new member's physician is contacted by telephone and asked to confirm the diagnosis. We asked if I.V. drug abuse was a problem experienced by members within the Coalition. We were told that to their knowledge I.V. drug abuse is not a problem. It does not occur within the Coaliton.

Kevin Brown indicated to us that A.Z.T. in British Columbia is not provided entirely free of charge, and this has created some problems for their members. Pharmacare, however, does pay 80 percent, with the client expected to pay the remaining 20 percent. In addition, we were informed the Province of British Columbia will not provide funding to either AIDS Vancouver or the PWA Coalition as, "The province views AIDS as a moral issue." The Coalition has received a grant from the federal government and has applied once again. We were told that the City of Vancouver is most supportive of this group, and they expect to receive funds from the City of Vancouver this year.

City of Vancouver - Vancouver Health Department

On the afternoon of June 9 we met with Dr. F. J. Blatherwick, Medical Health Officer; Sandra A. James, Health Planning & Policy Analyst; and Linda Rose, Coordinator of the Home Care Program Nursing Division, City of Vancouver, Health Department. Printed material was obtained from these individuals in relation to our discussions on AIDS and individuals who test HIV-positive, and is available at the Task Force office. Of particular interest in this package of information is a manual on the provision of home care for the person with HIV or PWA, as well as a handbook for caregivers. We were given permission to utilize all or any portion of this manual or handbook, provided recognition was given to the City of Vancouver, Health Department, for its production. It would appear, with the exception of the Home Care Program operated through the City of Vancouver, Health Department, that, as in San Francisco, all other services are brokered out to self-help, self-interest groups. It was noted by Linda Rose that the provision of home care is indeed not an inexpensive service. She indicated that home nursing care is provided, and the cost of each visit is $40.00, up to a maximum of three visits per day. All other home care services are added to this price.

AIDS Vancouver

On June 10, we met with Brian Peel, the Executive Director of AIDS Vancouver. We were told that AIDS Vancouver consists of a staff of ten and has had a total membership of 400 PWAs, living and dead. This group obtained federal and city funding, which amounts to the principal portion of their operating budget. They receive no provincial funding whatsoever. They must submit a program design, and they are expected to do some fund raising. These funds are provided to fund the infrastructure only. Recently, they have acquired a half-time, fund-raising person.

AIDS Vancouver provides educational and support services to individuals who have AIDS or who are HIV-positive. It was noted by Mr. Peel that education can reach a saturation point in the gay community; however, it must continue to be general and ongoing. He further noted that it has been learned that you cannot change pathological behaviour through education. Some special groups are now trying to be reached; for example, the seeing and hearing impaired; natives; and I.V. drug abusers. They have a program called "Train the Trainers."

We were told that through experience AIDS initially was viewed as a middle-class, gay male disease. It now has broadened to others who are in greater financial need. Therefore, AIDS Vancouver has an emergency needs fund which they use to provide financial assistance to "others" for items, special needs, etc., which are not covered under the general social assistance framework.

AIDS Vancouver has a volunteer component of 325 individuals -- 2/3 are gay male; 1/3, non. They have a volunteer coordinator and, as well, have developed a volunteer screening tool much like that used by the Big Brothers organization. All training of individuals in all areas, whether it is program, support, volunteer, etc., is done jointly so that individuals get a feeling of belonging to the whole organization.

AIDS Vancouver provides support services. People assist others to wade through the bureaucracy; as well, now this organization has gained a sense of credibility with government and the community. In addition, they now have weekly meetings with representatives of the Public Health Department, Infectious Disease Unit, and AIDS Vancouver. These weekly meetings are held at St. Paul's Hospital, at which time the group reviews client files and broker-out services according to the needs identified.

AIDS Vancouver provides in-service sessions to groups such as public health groups in other areas of the province. They have also developed an early contact with the British Columbia Psychological Association, which provides professional counselling sessions on a one-to-one basis, free of charge, or in professionally supervised group therapy sessions. All counselling, whether professional or through support groups, is now free to the client; but we are told by Mr. Peel they may start charging on a sliding scale basis.

Lastly, we were informed that AIDS Vancouver has hired a person, a half-time position, to deal strictly with individuals who are HIV-positive. There did not seem to be a feeling generated from these discussinos with Mr. Peel that funding was an issue. While they are expected to do fund raising, they have not found that this has been an absolute requirement to date. In addition, this group has an excellent relationship with the city's Public Health Department; and one got a real sense from speaking with Mr. Peel that AIDS Vancouver has not to date strayed from its original philosophy, and that is providing support to individuals, primarily, and education.

Comments and Observations on the Visit to Vancouver

It appeared to the observers that there is a broad range of coordinated services currently available in the Vancouver area for the provision of care and treatment of individuals with AIDS. Direct health care, home care, and social services are being provided through the public sector; i.e., St. Paul's Hospital, Vancouver City Public Health and Home Care Services, and the Social Services Department; with private groups and agencies, i.e., AIDS Vancouver and the Vancouver P.W.A. Coalition, providing advocacy, personal and psychological support, and assistance in accessing established services.

Annex A

AIDS Day Care Service Center is a community-based day program providing a variety of health, therapeutic, and social services for PWAs no longer able to manage independently at home. Modeled upon the existing Adult Day Health Care and Alzheimer's Disease Day Programs, ADCSC is a comprehensive and cost-effective alternative for PWAs for whom hospitalization may be inappropriate and costly.

San Francisco's response to the AIDS epidemic has set the standard for the country. However, recently completed research by the San Francisco Department of Health, as well as input from AIDS direct-service organizations, has confirmed that sizable gaps exist in the health care delivery system for PWAs, AIDS-related dementia, substance- abuse problems or medical problems requiring intravenous antibiotics or transfusions. San Francisco has no adult day health program for PWAs. Dementia, in particular, is becoming increasingly prevalent in the PWA population, challenging support services and requiring new treatments. A top priority for ADCSC, therefore, is to establish a program which meets these growing needs.

Program Goals and Objectives

AIDS Day Care Services Centers, Inc.'s evolving mission is threefold:

1) The primary goal of ADCSC is to generate a model for an AIDS-specific Adult Day Health Care Program with a specific component on dementia, which can be combined within existing ADH Progams or developed into smaller-scale independent programs at the state/national level. For example, once licensed by the state, the 60+ Adult Day Health Centers that currently exist in California could be eligible to accept PWAs into their programs.

   Objectives:

   - To develop an operational manual, enabling replication of the program model by other associated service organizations.
   - To increase knowledge of the treatment and management of AIDS-associated dementia in an Adult Day Health setting.

2) Another goal of ADCSC is to provide a supportive, culturally sensitive, and therapeutic environment for the delivery of services which enable the participants to continue to live in an active and meaningful way at their individual levels of ability.

   Objectives:

   - To utilize a coordinated multidisciplinary (medical, nursing, social, and therapeutic) approach to the delivery of services.
   - To increase networking with Adult Day Health Programs, direct service AIDS organizations, hospitals, and other providers in order to develop a program that will fill many of the gaps that currently exist in the health care options available to PWAs.

- To maintain bilingual and minority represented staff sensitive to the psychosocial and health needs of all PWAs.
- To incorporate specific services that meet the differing health, social, and emotional needs of women with AIDS.

3) A final goal of the program is to provide physical and emotional respite, education, and support to caregivers, thereby helping to alleviate the burden created by prolonged periods of time spent caring for PWAs.

Objectives:

- To offer emotional support groups on a consistent basis to caregivers of PWAs, in particular to those individuals providing care for participants with AIDS-related dementia.
- To increase educational and community outreach activities which explain the services of ADCSC, with a special emphasis towards the Hispanic community.

Methods

The provision of comprehensive and coordinated AIDS Day Health Services will be accomplished by the efforts of a multidisciplinary team. This team consists of regular staff members and consultants of AIDS Day Care Service Center. Though emphasis is put on involvement of all staff members, the primary responsibility is carried by the: Program Director, Medical Director, Social Workers, Nurses, Occupational Therapist, Activity Coordinator, and Program Aides. These health professionals conduct a comprehensive assessment of each particpant to determine what services fulfill the individual's specific health and social needs. The individualized plan may include:

- Nursing Services
- Infusion Services
- Personal Care Service
- Occupational Therapy
- Recreational and social activities
- Caregiver Support Services
- Dementia Program
- Psychiatric and psychological services
- Hot meals and nutritional counselling
- Transportation to and from center

Eligibility

ADCSC is for all PWAs with physical/mental impairments that handicap activities of daily living but are not so serious as to require 24-hour institutional care and have a high potential for further deterioriation and probable institutionalization if ADCSC were not available.

Individuals who meet the following criteria will be eligible for admission to the program: 1) Can profit from participation, 2) Are not bed-ridden, and 3) Should not be alone during the weekday.

Participants shall be accepted to AIDS Day Care without regard to race, sex, colour, creed, mental or physical handicap, religion, sexual orientation, or national origin.

Fees

ADCSC services are reimbursed by MEDI-CAL, private insurance or private payment. A sliding scale fee schedule exists based on participant's ability to pay.

Hours of Operation

The general operating hours of the Center are from 7:30 a.m. to 6:00 p.m., Monday through Friday, with the exception of national holidays during which the Center will be closed. Participants are scheduled to arrive at the Center between 9:00 and 10:00 a.m. and depart between 3:00 and 4:00 p.m. Adjustments may be made in the hours or days of operation to accommodate working caretakers and other special circumstances.

Funding

Startup funding is actively being sought through government and foundation grants, as well as private donations. To date, the operating expenses of $30,000 have been secured from: The San Francisco Foundation, Kaiser Foundation, Castro Lions, and direct donations. When fully operational, we expect 70% of the operating budget to be covered by medical and insurance reimbursement.

We have an active volunteer staff. We are pleased to accept donations of office or program equipment. Our current volunteer needs are for office assistance and fund raising.

For further information:

Mailing address	2370 Market Street, Suite 114 San Francisco, CA 94114
Office address	333 Valencia, Room 251 San Francisco, CA
Telephone	391-2555

Annex B

SHANTI PROJECT – Support Service for People with AIDS and Their Loved Ones
Howard Street
San Francisco
California 94105
415-777-CARE

An Overview of Shanti Project

SHANTI HISTORY

- Shanti is Sanskrit for "Inner Peace".
- Founded in 1974 by Dr. Charles Garfield to provide support services for persons with life threatening illnesses and their loved ones.
- Shanti Project is a private non-profit organization eligible to receive tax deductible donations under California State 501(c)3 statutes.
- November 1981, started first San Francisco support group for people with AIDS.
- December 1983, programs were limited to serve only PWAs and their loved ones in San Francisco.
- 1981 to 1988:
  - Programs increased from 1 to 6.
  - Number of clients increases to over 4,500 people with AIDS and their loved ones annually.
  - Paid Staff increases from 1 to 67.
  - Of the current staff, approximately 45% are women and 30% are ethnic minorities.
  - Budget increases, from a deficit of $4,000 in fiscal year 80-81, to $2,900,000 in fiscal year 87-88.
  - Approximately 1/2 (or $1 million) of the Shanti budget is currently provided by the San Francisco Department of Public Health.
  - The active volunteer body increases to over 600 individuals, comprised of women and men who are ethnically, age, linguistically, sexual orientation and socio-economic status diverse.
  - It is estimated that Shanti Project volunteers save the City of San Francisco approximately $7 million annually by providing humane and compassionate direct services.
- The Shanti philosophy of service provision is based on enhancing quality of life for those living with AIDS, and people helping people in time of need.
- Shanti services are available for all people with AIDS and their loved ones residing in San Francisco.
- Current clients include men, women, and children from a variety of ethnic, cultural, and socio-economic backgrounds as well as active and recovering substance abusers and IV drug users.

SHANTI PROGRAMS

EMOTIONAL SUPPORT

- Services are provided free of charge.
- More than 370 volunteers annually commit at least 6 months, 8 hours a week to providing service.
- Volunteers go through an experiential 44 hour training before beginning service.
- Volunteers meet weekly in their own small support groups with other volunteers providing similar services.
- One-on-one peer counselling.
- Weekly drop-in emotional support groups for people with AIDS and their loved ones.
- Specialized support groups available for women with AIDS, women who have a loved one with AIDS and children who are diagnosed themselves or coping with a loved one's diagnosis.
- Serves over 2,200 people with AIDS/Severe ARC and their loved ones annually.
- Cost to provide services: $4.08/hour.
- This year volunteers and staff will provide 127,000 hours of free counselling. Next year it is projected 156,000 hours will be provided.

PRACTICAL SUPPORT

- Services are provided free of charge.
- More than 250 volunteers annually commit at least 6 months, 8 hours a week to providing service.
- Practical Support Volunteers go through a 22 hour training program before they begin service.
- Volunteers provide house cleaning, laundry, childcare, grocery shopping, cooking, moving, and other errands.
- Volunteers meet regularly in support groups with other volunteers providing similar service.
- Van service transports 80 individuals weekly for medical appointments.
- Serves over 1,300 clients annually.
- Cost to provide services: $6.06/hour.
- This year volunteers and staff will provide 64,000 hours of free volunteer support. Next year this is projected to be 87,000 hours.

RESIDENCE PROGRAM

- 12 multi-person apartments with a total of 47 residents in an independent-living environment, with each person having their own private bedroom and sharing the common living area.
- Rent limited to 1/4 of individual's monthly income.
- Services available for adult women, men, and emancipated minors.
- Housemeetings and service arrangements through staff resident advocates.
- Serves approximately 95 people with AIDS/Severe ARC annually.
- Cost to provide services: $37.13/day.

COUNSELING AT SAN FRANCISCO GENERAL HOSPITAL

- Services are provided free of charge.
- Peer counseling for inpatients and outpatients provided by Shanti staff.
- Support groups also available on-site at SFGH for family members/loved ones of inpatients who have AIDS.
- Serves over 3,000 people with AIDS/Severe ARC and their loved ones annually.
- 30% of all clients served at SFGH are ethnic minorities.
- Cost to provide services: $25.58/hour.

INFORMATION AND REFERRAL

- Services are provided free of charge.
- Receives and answers more than 600 incoming calls and inquiries daily.
- Administers people with AIDS Recreation Program, which:
  - acts as clearing house for donated tickets to cultural and social events;
  - provides special recreational activities and programs;
  - creates and distributes monthly newsletter for Shanti clients.
- Cost to provide services: $3.48/contact.

PUBLIC EDUCATION

- Maintains a Volunteer Speaker's Bureau to address the AIDS physhosocial needs of the S.F. Community.
- Coordinates volunteer recruitment advertising campaigns.
- Coordinates National Training Program.
- Markets 27-tape Video Training program and printed manuals.
- Produces and distributes newsletters and pamphlets which promote project programs and volunteer service delivery.
- Coordinates media outreach.
- Cost to provide services: $5.00/contact.

Rev. 6/3/88
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Report to Chairman, Nova Scotia Task Force on AIDS:
Visit to Boston

June 6 and 7, 1988

Representatives

Mrs. Marlene Grantham
Member of the Task Force

Mr. Robert Davies
Department of Advanced Education and Job Training

Mrs. Joan Redmond
Department of Community Services

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

Boston Visit Re: AIDS Task Force

Information about the prevalence, care and attention being paid to AIDS in the Boston area was acquired from a number of sources and is reported here as general information, rather than documented epidemiological facts.

There are approximately 400 AIDS cases in Boston now, and there is a projection of 4,000 in the next 10 years. A number of government, commercial and voluntary agencies are attempting to work collaboratively to address the many needs – both health and social – which arise because of this disease.

In the Boston area, apparently 60 per cent of AIDS patients can be attributed to homosexuality alone. Only 2 per cent are of haemophiliac origin. Approximately 15 per cent of AIDS patients are Latino and people of colour and they are beginning to see a significant number of women with the disease.

An interesting observation was made in relation to AIDS and IV drug users: the rate of AIDS with IV drug users is highest in those states where people are not able to buy needles and syringes across the counter. In the mid-west and western states, where these can be purchased without prescription in a drugstore, the rate of IV inflicted AIDS is much lower.

Education about AIDS is integral to the total picture. Educating health care workers about the disease is one focus. One position is funded through Public Health Department funds in the voluntary organization, the AIDS Action Committee, with this priority. Education done through the official agency of the general public and others is limited and restricted in terms of the explicit nature of material. Voluntary agencies are able to be more explicit in their education programs, and gear the nature of their programs to the audiences. For instance: more explicit homosexual material is geared to the gay community, etc. Education in the Boston and New England school system about AIDS is throughout the school years; however, the education is not as effective as it might be because it is not allowed to be explicit. Apparently the rate of teenage pregnancies is extremely high in this area.

Recently federal grants have been given through National Mental Health Institutes for research and education into AIDS. The New England States have received a portion of these grants and are developing educational programs which will probably last over six weeks with perhaps 2-3 hours a session. These educational programs would be geared to health care workers at various levels.

The Deaconess Hospital in Boston has the largest percentage of AIDS cases in New England. They have two Nurse Specialists working with the development and education and specialized services for AIDS patients. The Brigum and Women's Hospital has a Co-ordinator of Education and In- and Out-patient Services for AIDS patients. To prevent burnout of hospital staff dealing with AIDS patients at the Deaconess Hospital, a family night is held to provide information and support to the families of health care workers caring for AIDS patients.

Human rights laws in this area prohibit discrimination against persons with AIDS. Apparently the laws are sufficiently vague that they make reference to perceptions of AIDS. Although it does not cover HIV positive workers, it may be included in the perceptions. AIDS is classified as a disability.

The Boston Visiting Nurse Association has been providing home services to AIDS patients for the last one-and-a-half years. This organization is the second largest visiting nurse association in the United States, making half a million visits per year to 12,000 patients. They employ a staff of 680 people, including 106 Nurses, 100 Home Health Aides on salary, a considerable number of hourly and contract Home Health Aides and R.N. Staff, and also a rehabilitation staff of Occupational and Physio Therapists. Every month they conduct a two-week training program for Home Health Aides, which includes approximately two days of education on caring for AIDS patients; however, at the present time, they have a core group of about 15 Home Health Aides who will provide support to AIDS patients. Burnout in these workers is a concern, and the agency is starting to recruit from Latinos and people of colour, in addition to their current recruitment campaigns, for these workers. This is the only group of their home service personnel who are particularly dedicated to AIDS patients. All other personnel – i.e., professional nurses and the rehabilitation staff – care for the AIDS patients as they appear in the district assigned to them. This concept of integrating AIDS patients throughout the staff has been done very deliberately to maintain a generalist approach. The VNA began a year-and-a-half ago with 10 AIDS cases and today have between 40 and 50 on their caseload, and they're expecting this rapid increase will continue.

The VNA has considerable problems with personnel recruitment and have difficulties with low salary rates. Home Health Aides are paid approximately $6.00 - $7.00 an hour for physically hard and emotionally exhausting work. Compare this to a pizza service deliverer at $7.00 an hour (work available in the same community), and you can appreciate their recruitment dilemma. Another recruitment dilemma is in relation to Registered Nurses. There is an acute nursing shortage across the United States; and Boston hospitals have recently gone into a wage war, with wage increases in the neighbourhood of 25 per cent being offered in the local hospitals. The VNA have recently received approval to change their per visit fee and are now able to also offer a 25 per cent increase to their Nursing staff.

For additional information, see report of Joan Redmond, as Annex 3.

The AIDS Action Committee was originally started as a 10-member voluntary committee interested in the health of gay men and attached to the main gay organization in Boston. It has grown to a staff of 55 and is now a separate organization, although it maintains the name AIDS Action Committee. Their primary focus is on education and advocacy. They have a budget, I estimate to be approximately six million dollars and receive 40 per cent of this from government funding of national, state and local sources, and the remainder through extremely innovative private sector fund raising. We were told that they can mount 60 special event fund raisers a year and have significant financial support from each. Their recent Sunday Walk was targeted for $800,000 and brought approximately $1.3 million. We were told that the gay community in Boston is very large and many are well to do.

The AIDS Action Committee has four parts to its mission:

(1) To provide service and support to persons with AIDS and AIDS-related conditions and their friends and families;

(2) To provide education and prevention services (education to prevent the spread of the disease);

(3) To advocate for quality service and education through government and other agencies; and

(4) To provide outreach linkages with services available as broad a base as possible. They have expanded from gay men focus to support of people of colour and women, as these groups grow in the incidence of disease.

The Client Services Director told us they support mandatory reporting for the creation of statistics which helps them provide a focus on education to target populations for prevention activities. Copies of a considerable number of educational pamphlets which are geared very specifically to select target publications were collected and are in the Task Force office.

The AIDS Action Committee has 1,100 volunteers placed in a variety of programs and activities. It would seem the volunteer committees or sub-committees focus on issues as specialized as psychological support. The trainers for other health care providers are trained this way. They have a Buddy Program which is based on the Shanti Hospice System of California, and material on the training program which is given to these buddies is in the Task Force office.* A hotline is operated, mainly by volunteers, from 9:00 a.m. until 9:00 p.m. Apparently there is a considerable network of specialist hotlines in the Boston area, and they refer to each other. For instance: there's a Teens Hotline, a Spanish Hotline, etc.

The AIDS Action Committee acts as a facilitator to help coalitions of persons with AIDS organize themselves in ways that make sense to themselves. The AIDS Action Committee provides them with funding and logistical support. For example: publishing a newsletter written by members of the coalition. However, it is difficult organizing these groups as the virus is their only common denominator and they do often have little other factors in common. Another difficulty is that the leaders often become too ill to carry on. The AIDS Action Committee do have on their staff PWAs and persons with ARC and have had some of their staff die.

A new venture for the AIDS Action Committee is the development of an AIDS In the Workplace Program. This program, when it is developed, will have three focuses: (1) basic education on how the disease is contracted and how to prevent this. This is a general, basic education for the members of the workforce. (2) The second phase is geared to Personnel Managers regarding policies which are AIDS-sensitive, and (3) the third phase is a train-the-trainer program so the industry or employer will have their own staff to maintain the state of knowledge of the workforce. These programs will be marketed for a considerable profit to various employers in the New England States.

A phrase that we heard very often was "linkages". Apparently the AIDS Action Committee places considerable emphasis on working collaboratively with other organizations and in developing supportive and complimentary relationships with the 8+ agencies primarily concerned with AIDS care and services in Massachusetts.

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* See Annex 2.

We also learned that AIDS Action Committee has 11 beds available for PWAs and ARC in two geographical settings – one in town with five beds near hospital and one in suburb with six beds. Persons must be independent or needing only visiting support to be eligible. Their beds are held for six weeks if/when they are hospitalized. More terminal people can be transferred to a suburb long-term facility unit of 10 beds. Within the year, a 20-bed hospice unit near a hospital will be opened. Otherwise, terminal care is in-hospital or occasionally in other chronic care institutions.

For further information about home care being co-ordinated by the AIDS Action Committee, see report written by Joan Redmond in Annex 4.

It would seem from the contacts made in Boston that there is considerable commitment to collaborative work on behalf of persons with AIDS and linkages being developed among the gay community, the health care providers and institutions to prove appropriate education to prevent the spread of this disease and appropriate and compassionate care of AIDS patients. An additional concern expressed by several people we contacted was appropriate support and education for the care giver. The networks and linkages among government agencies and community and voluntary agencies would appear to be extensive and although not perfectly effective, at least working at being mutually supportive.

Marlene Grantham
Joan Redmond
Robert Davies

August 15, 1988

Annex 1

Schedule of Meetings for Boston Trip
Re: AIDS Task Force - June 6 & 7, 1988

June 6 7 - 10 p.m.

Working dinner with AIDS Action Committee staff member, Jeff Huyett, Health Care Provider Educator (others scheduled were unable to attend).

June 7 9 - 11 a.m.

Visiting Nurses Association

Berit Pratt, AIDS Nurse Co-ordinator of Boston
Beverly Wancho, Assistant AIDS Nurse Co-ordinator of Boston
Jim McCarthy, Trainer, Home Health AIDS Courses (unavailable)

12 - 2:30 p.m.

AIDS Action Committee

David Aronstein, Director of Client Services
Larry Killian, Director of Finance
Kurt Reynolds, Housing Program Co-ordinator
Ken Smith, Co-ordinator, AIDS Hotline
Deane Perlmutter, Director, Home Care Advocacy

Annex 2

Review of Materials from AIDS Action Committee Boston

Robert V. Davies
June 1988

AIDS Action Committee Support Services Team Training Manual (revised April/May 1986)

Contents

Section I	AIDS, The Medical Picture What is AIDS? History of the Epidemic Epidemiology The Immune System
Section II	AIDS Related Illnesses & Infections ARC (AIDS Related Complex) Lymphadenopathy Opportunistic Infections Kaposi's Sarcoma
Section III	Diagnosis of AIDS Medical Treatment of AIDS Medical Treatment of Kaposi's Sarcoma Drugs Used Symptom Management
Section IV	Psychosocial Aspects of AIDS Meeting Psychological Needs Existential & Spiritual Concerns General Counselling Recommendations Empathy/Listening Skills
Section V	Precautions Home Care Guidelines Risk Reduction
Section VI	Stress Death & Dying Bereavement/Mourning Grief Suicidal Potential Expressions of Sexuality
Section VII	AIDS Resource List
Section VIII	News & Media Articles relating to AIDS

The purpose of this manual is to provide information and resources for persons with AIDS, their families, significant others and caregivers, which promote the ability to LIVE with AIDS.

New England Journal of Public Policy - Winter/Spring 1988

Outlines the major policies that the various States have adopted as well as major studies by various health organizations. In addition, there are policies governing introducing AIDS education in Connecticut schools.

From All Walks of Life

A book put out by the AIDS Action Committee for walkathons which took place June 5, 1988 and raised $1.3 million.

Green Folder

Is a support folder providing information for support and advocacy for AIDS victims and their families.

Hot Line Program

Indicates the availability of a Hot Line for information on AIDS as well as support for AIDS victims. Includes an application form and an annual report.

Housing Services Manual

Outlines the services available for people with AIDS. The residence program policies are also outlined.

AIDS in the Workplace

Outlines the history and program of AIDS in the workplace. This is a program that will generate funds for the AIDS Action Committee.

Financial

This folder includes the budget for the AIDS Action Committee for 1988 and their operational strategies.

Client Services Department

This outlines what is available from the Client Services Department.

Client Services 1st and 2nd Quarter Report

The mission of the Client Services of AIDS action is to provide high quality staff and volunteers. Provides services to people with AIDS/ARC and their families/friends and to advocate for high quality medical and social services for people with AIDS/ARC delivered by other service providers.

Various Pamphlets

Material Acquired by M. Grantham in Relation to Nova Scotia Task Force on AIDS Visit

I. *Material from AIDS Action Committee of Massachusetts*

1) Large white binder used for volunteer training in buddy support system.

In the front of this binder are several miscellaneous pamphlets on AIDS, advice to the volunteer on legal questions concerning suicide and a copy of an AIDS newsletter produced monthly from the Massachusetts Department of Health/ Boston Department of Health and Hospitals. Also at the front of the binder are policies in relation to the volunteer program and a schedule for the course, including two weekends consisting of Friday night, Saturday and Sunday.

Section One includes:	AIDS - The Medical Picture What is AIDS? History of the Epidemic Epidemiology The Immune System
Section Two includes:	AIDS Related Illness and Infections AIDS Related Complex Lymphadenopathy Opportunistic Infections Kaposi's Sarcoma
Section Three includes:	Diagnosis of AIDS Medical Treatment of AIDS Medical Treatment of Kaposi's Sarcoma Drugs Used Symptom Management
Section Four includes:	Psychosocial Aspects of AIDS Meeting Psychological needs Existential and Spiritual concerns General Counselling Recommendations Empathy
Section Five includes:	Precautions Home Care Guidelines Risk Reduction
Section Six includes:	Stress Death and Dying Bereavement/Mourning Suicidal Potential Expression of Sexuality
Section Seven includes:	List of Local AIDS Resources Information on Legal Issues from People with AIDS and ARC Information on Videos
Section Eight includes:	Selected mimeographed material for the information of the trainee

2) First and Second Quarter Report - July/87 - December/87 of client services and Fiscal Year Report, 1987. July/86 - July/87 of Client Services Department (includes statistical and narrative description of client services offered).

3) A program brochure on the Second International Lesbian and Gay Health Conference and AIDS Forum to be held July 20-26/88 in Boston.

II. Visiting Nurses Association of Boston

1) San Francisco AIDS Foundation: AIDS Educator Catalogue
2) A brochure on "Too Little, Too Late", a video documentary about families of AIDS patients.
3) Weekly statistic tracking of AIDS caseload and photocopy of Boston newspaper article about VNA service.
4) Alphabetized list of VNA/Hospice DPH grant recipients.

Marlene Grantham

Annex 3

Report

Ms. Berit Pratt, AIDS Nurse Coordinator
Visiting Nurses Association of Boston
23 East Street, 2nd Floor, Maple Leaf Building
Cambridge, Massachusetts (617) 577-7900
June 7, 1988

Berit Pratt is the AIDS Nurse Coordinator for the Visiting Nurses Association of Boston, and Beverly Wancho is the Assistant Nurse Coordinator for the AIDS Program with the Visiting Nurses Association of Boston.

This report is specific to AIDS training for homemakers, home health aides and service delivery to people with AIDS by this staff level.

The Visiting Nurses Association of Boston began one and a half years ago delivering service to people with AIDS. As their hiring policies with home health aides they have recruited people specifically interested in working with AIDS. Because of the critical shortage of workers they have very little criteria for their staff, especially at the home health aide level. The main criteria seems to be the fact that they are willing to work with people with AIDS. They have attempted to recruit home health aides from the gay community and from the various cultural groups, especially those who have a high instance of people with AIDS. They employ a psychiatric social worker who works closely with the home health aides who are going into homes of people with AIDS, and they have noted that there is a high rate of burnout amongst the staff.

The Agency has a person hired specifically as a trainer for the home health aides. His name is Mr. Jim McCarthy. We were unable to meet with Mr. McCarthy. We were unable to speak with him on the phone. Bob Davis, of the Department of Advanced Education and Job Training, will be following up with a phone conversation with him.

Jim McCarthy offers a training course for home health aides on a monthly basis. It is a two week course of 60 hours in total, and two days of this course are devoted to AIDS information and the caring of people with AIDS. There is no written course curriculum. This two day program on AIDS is called "AIDS 101", and it is given to both nurses and home health aides. A feature of this two day program is a talk given by a person who has AIDS. A nurse, who has had a brother die from AIDS, talks on the aspect of family involvement and concerns. She deals with the very humanistic approach of dealing with PWAs.

AIDS 101 is dealing mainly with AIDS and the homosexual element. Apparently there is work under way to do an "AIDS 102" which will be dealing with AIDS among drug abusers. This would include concerns of the IV drug user, the family situation, the socio-economic concerns as well. There will be further expansion of attitudes on the gay community, and this will include a session on homophobia. The Boston Visiting Nurses Association realizes that there is a major concern in approaching and dealing with the Haitian people. They have a very strong but closed culture. They are very cautious and very suspicious of outside influence and do not seem to want any help dealing with AIDS or any AIDS information education.

Home health aides are hired by the Agency. They are then trained and the cost for this training is covered by the Agency. One aspect of their training sessions or information sessions on AIDS that I was particularly impressed with was a "Family Evening" where family members of staff can come in and have an information session on the disease and the care givers responsibilities. This type of outreach to the families of staff caring for people with AIDS seems to help with lessening the burnout of staff.

Home health aides are hired by the Boston Visiting Nurses Association on staff with a salary of $6.50 and $8.50 an hour and they have some benefits. They also have part-time or casual staff who are paid $6.00 an hour. They have no benefits. They also contract out services to other agencies when they are short on staff themselves. The home health aides are supervised by a nurse. They are supervised probably every four to six weeks with normal clients. With a person who had AIDS they are to be supervised on a weekly basis. This supervision is provided to the staff as well as to do a reassessment of the client himself. The assessments are often done the first day the home health aide goes in. During this assessment the nurse and the home health aide go over the responsibilities the home health aide will assume. It is interesting to note the Agency feels case management of a person with AIDS takes three times as long as one of their other clients and that the nursing services are twice as long. They are concerned with quality assurance, given the worker shortage and the low salaries. They freely admitted they would hire just about anybody who would be willing to go in and work with a person with AIDS.

In case management of people with AIDS at the Boston Visiting Nurses Association the staff who do provide care to people with AIDS are given the diagnosis, and the actual diagnosis is maintained in the client file. They are not kept separate or tagged in any different manner. They are attempting to treat people with AIDS in the same way as they treat all their other cases.

They would like to have their staff generalists and not specialists in any particular field. There has been no problem with this. The nurses just accept a case as any other in their district. They have not had a staff member, be it a nurse or home health aide, refuse to go in to care for a person with AIDS. They feel this is mainly due to their in-services they have had on the disease itself.

The cost for any home care services is covered either by the client's own personal insurance company or through Medicaid, which is the State Medical Insurance Program. Medicaid is available for people over 60 or those under 60 who have severe financial limitations.

(Mrs.) Joan Redmond
Assistant Coordinator
Home Care Program

Annex 4

Meeting Report

Boston, June 7, 1988
Diane Perlmutter, Home Care Coordinator
AIDS Action Committee
661 Boylston Street
Boston, Massachusetts 02116
Phone (617) 437-6200

Diane is a Home Care Coordinator for the AIDS Action Committee.

My meeting with Diane had not been scheduled and as a result we had a very short time for our discussions.

Diane comes to the AIDS Action Committee as a relatively new employee. She came from a Home Care Program that delivered services to elderly people, mainly people with Alzheimers disease. She sees a strong correlation between the needs of those with Alzheimers with AIDS who are suffering dementia and people with AIDS who are suffering a form of HIV dementia.

Diane sees her position with the AIDS Action Committee as one of a policy planner and an advocate for the establishment of new services for people with AIDS. She would like to develop programs such as day programs, foster care homes, medical transportation and meals on wheels. These are programs that are offered to the elderly. She is not certain that she can access those services as they are now structured for people with AIDS or if she will have to establish a parallel structure.

Diane is also concerned about in-home care for people with AIDS, those services that are delivered by a homemaker to enable the person to stay at home and remain as independent as possible. I use the term "homemaker" because when she described the services she wanted to see delivered in a home, they are services that homemakers in Nova Scotia deliver. In Boston there are several levels of care. She finds these levels unnecessary and very confusing to both the client and service providers.

There are three basic levels of care that could be combined into one. The first level is a homemaker who does only the physical housekeeping tasks, meal preparation and shopping. The second level is a home health aide who does not do these jobs but is involved in the hands-on basic personal care and emotional support. Then there is the personal care attendant who looks after dressing, grooming and assistance with ambulation. It was my impression that the personal care attendants are involved in care to disabled younger persons.

Diane expressed grave concerns about the Home Care structure in Boston and in the State of Massachusetts; she feels that it is at such a critical state it may be close to collapse. There is a critical worker shortage, especially in the lower level of care.

Home health aides are paid between $5.00 and $7.00 per hour. Their work is very isolated. There is a fair amount of down time and her feeling was that the training was rather poor. The unemployment rate in the State of Massachusetts is only 3 per cent. There are many other jobs that pay better wages and have better working conditions. For an example a person who delivers pizzas gets at least $7.00 per hour. Therefore the incentive to work in the home health aide, homemaker or personal care attendant field is not very great. At the professional level there has been a wage war in effect with the various hospitals in Boston trying to encourage nurses to work for their institutions. The wages for nurses in the hospitals have been anywhere up to $10,000 more than nurses who are working in Home Care. It was only within the last couple of months the Home Care field has been able to obtain permission to increase the salaries of their visiting nurses to the point that they are competitive with hospital staff.

Diane would like to establish a Home Care Program for people with AIDS comprised of a home health aide/homemaker who could do all the in-home support services such as meal preparation, care of the home itself, basic personal care, everything that would be needed to enable the person to stay at home excluding nursing services. She would also like to see a strong volunteer component involved in transportation, meals on wheels and the day programs. This is not to say that the visiting nurses are unnecessary. They would be a strong component in the in-home care to people with AIDS. She hopes to establish a system of foster homes where people with AIDS who are no longer able to remain by themselves can go and receive care and the emotional support they require within a home-like environment.

Diane was very interested in our Home Care Program here in Nova Scotia. She is interested in learning more about our program and how we intend to develop our care and especially care for people with AIDS. She is interested and willing to participate with an exchange of information if this would be beneficial to both Home Care Programs.

Joan Redmond

Summary of Recommendations and Comments from Public Meetings

From the written submissions, a total of seven hundred and forty recommendations were extracted. After removing repetitious recommendations, two hundred and forty-six recommendations remained. Many of the comments, although of value, could not be considered by the Task Force within the scope of its work.

Issue	**Recommendations In Briefs**
EDUCATION Co-ordination Central Authoritative Source of Information	
Response to misinformation	Government should present people with honest assessment of the reality of the disease.
	Task Force should accept some responsibility for refuting irresponsible public comments re quarantine of those testing HIV +.
Response to misinformation	Public Anxiety Nourished by Irresponsible Coverage (PANIC) is often spread by contact with the news media who deal with the truth in a promiscuous & casual fashion, bringing them into frequent contact with distortions, misconceptions and outright lies.
Approval of government circulated information	Establish a Secretariat On AIDS to be a central coordinating agency for government policy and information on AIDS.
	The Departments of Health & Education should continue to work together to provide school systems (and other employers) with updated information and educational materials relating to AIDS as APPROVED & RECOMMENDED by medical & educational professionals.
	It is essential that basic information be, and be seen to be, reliably and systematically generated from one authoritative source (the Department of Health).
Central resource centre/clearinghouse	Establish an AIDS Resource Centre at the Victoria General Hospital.
	We would recommend the establishment of a central clearing house in Nova Scotia for information on AIDS that is readily available and current.

	AIDS ed. of university students needs to be ongoing. Each university library should be supplied with books & other resources on AIDS ed., and this information should be continually updated.
Hotline	Accessible telephone help lines could provide education and counselling, particularly to the hard to reach populations such as married gay men and bi-sexuals, who may be reluctant to seek information without guarantees of anonymity.

EDUCATION
Co-ordination
Co-ordinating Agency

Co-ordination of all educational/support efforts public, private & voluntary	The Advisory Committee on AIDS, an independent agency funded by the province would have representation from medical community, social workers, education, Gay community, volunteer groups, Red Cross, Canadian Hemophilia Society, etc., to advise government.
Assistance for the development of voluntary role in network (consultation and funding)	Government must play a strong leadership developing cooperation among helping agencies, educational institutions, churches and public bodies. The government fund organizations similar to MACAIDS for establishment across the province, such organizations to receive training and guidance from MACAIDS or an organization of individuals with a like-minded approach and analysis of issues.

EDUCATION
Co-ordination
Role of Non-profit Agencies,
Volunteer Networks and
Community-based Organizations

Role of agencies, networks and organizations	We should utilize an amazing network of professional organizations, unions, church and community groups, provincial newsletters and local media in Nova Scotia, to make this huge task a more manageable one.
Role of agencies, networks and organizations	We feel our hospital has a role in education & prevention which will continue to require increasing attention. The identification & treatment of many of society's ills respond well to education & preventive measures.

EDUCATION
Co-ordination

Role of Media

Establish an AIDS Education Committee with representation from the media, Government and medicine.

Establish an AIDS Education Campaign directed at patients using material in physician's offices throughout the province.

More educational programs must appear on television and advertising should appear in taverns and dance halls where young people meet.

Most Nova Scotians rely on the media to involve them in this important public debate. The media have failed them badly. Instead of informing the public, the media, with a few exceptions, have chosen to market only the most sensational tidbits.

AIDS & other STDs could all be prevented if youngsters got information on safe sex practices from the same media that often promotes sex through music, programming & advertisements.

The mere presentation of factual information about AIDS will not in itself change the attitudes & practices of those who hear it. The information must be repeated, discussions must be encouraged and the wider social implications explored.

Role of Media

The issue that makes any problem in AIDS education so difficult or controversial is the notion of "safe sex". The degree to which this concept can be interpreted is widespread. Most resources & program guidelines lose community acceptance due to this.

EDUCATION
Target Audiences
General Public

Government sponsored program
comprehensive multi-media campaign

Develop program to reach sector ignoring or unable (due to illiteracy) to assimilate existing information.

AIDS education programs should be frank and descriptive. "Efforts to offend no one, educate no one."

Develop education programs designed to remove fear and ignorance about AIDS and carriers of HIV.

Public education should focus less on non-traditional lifestyles and more on accurate information on modes of transmission.

The government should embark on a comprehensive AIDS education program using the mainstream media, incorporating and reflecting all forms of sexual orientation, in a positive or at least neutral fashion.

In developing plans for education, existing sources in the gay community should be adequately funded and should be utilized in the provision of education outside the gay community.

Government sponsored program comprehensive multi-media campaign

It is recommended that the government increase funding to the Human Rights Commission to undertake the ongoing education process with respect to individual rights of those affected by the virus.

Public AIDS education programs must allow and encourage people to confront their own attitudes towards homosexuality and to honestly separate fear of the disease AIDS from homophobic reactions.

We would strongly support a Task Force recommendation that public education be greatly enhanced. We offer the dental offices of the province as an avenue for information dissemination, assisting the Department of Health & Fitness with their education challenge.

A full time staff person to work with Public Health offices, who could arrange to meet with any groups, clubs & organizations in a given area could reach those outside the school system.

Revoke the censorship of contraceptive advertising. Telling our teens about condoms is not going to promote promiscuity.

We should provide a mobile education/ counselling unit to enable the rural population access to information/ contraception, i.e., protection will produce a positive spin-off effect by the prevention of STDs, reductions in abortions & unintended pregnancies.

Government sponsored program comprehensive multi-media campaign

Our politicians/government must establish a budget and mandate for a sexuality education specialist and resource persons in rural Nova Scotia areas.

Knowledge & information combined with clinical services can reduce STD transmission, & can help postpone sexual activity & support the choice to abstain. That information must come from parents, schools, media, peers & community workers supported by government.

In this situation, ignorance is not bliss.

It is estimated that 1 in 10 males are practicing homosexuals & 1 in 100 Canadians are infected with HIV. AIDS education programs should not assume that the audience is composed solely of heterosexuals & uninfected persons.

Individuals need to be made aware of the early symptoms of the disease so that medical treatment can be sought. Drugs do exist that can reduce damage to the immune system. Early detection, through education, must be a major goal in the fight against AIDS.

"AIDS education is not a moral issue, it's a matter of life and death."

EDUCATION
Target Audiences
Students

Curriculum

Elementary

All teachers of AIDS education programs must be qualified & suitably trained.

Elementary

At elementary level, program should be delivered by teacher responsible for other course offerings, due to experience in age-appropriate teaching methods.

The Department of Education should mandate if AIDS should be taught, at what grade levels, provide guidelines for teaching and provide current material.

I ask you to recommend a comprehensive program of AIDS information in the public school system beginning in grade 3. With the age of menstruation declining, we do have pregnant sixth graders in Nova Scotia. Junior High is too late.

Junior High School

Program should be included as part of comprehensive, age-appropriate health education curriculum such as PDR.

Program must address abstinence & other values-related topics.

Linking the morality of homosexuality to a response to AIDS results in inappropriate responses. This can be overcome by education.

Mandatory AIDS education at the secondary school level with an emphasis on safe sex practices and not just abstinence as the way to avoid AIDS, and incorporating positive or at least neutral reference to all forms of sexual orientation.

Junior High School

We feel strongly that Human Growth and Development should be a mandatory section of the PDR curriculum. We do feel that for those who strongly object to sex education, the Human Growth & Development section of the PDR curriculum should not be compulsory.

Senior high school

Marriage Preparation programs and Preparation for Family Living programs should be offered.

After this school year, all students entering high school will have been exposed to AIDS education in their junior high years & repeating the information in High School may be redundant unless new information becomes available.

Community colleges

Education programs & policy development should extend to non-university sector of post secondary education.

University

MACAIDS, the Nova Scotia Task Force On AIDS and Nova Scotia Student's Unions participate in the development of a comprehensive University AIDS education program, ensuring peer identification through Student's Union & using campus media.

Everyone presently in teaching or helping professions or those studying to enter these professions should be required to become informed on the issue of AIDS on a factual level & be exposed to a program ensuring their attitudes re PWAs are examined.

Information/Education Outside Curriculum

Senior high

School-age children need the ability to acquire latex condoms and spermicide without embarrassment. Providing such items to school-age children may or may not encourage "immorality". Not providing them does lead to death.

Teens have significant psychological barriers to openly purchase barrier contraception and protection. This is quite evident in rural Nova Scotia

	where there is one drugstore & everyone knows everyone. Anonymity is extremely difficult.
Universities	Universities be directed to establish a clear and public policy on AIDS prior to the end of 1988 and that student representatives participate in policy development.
Parents (familiarity with curriculum)	Allow for involvement of parents, teachers, students & appropriate community groups, both initially and ongoing.
	There is a need for parents to take a more realistic and responsible attitude toward educating their own children about responsible decision making and choices regarding their child's sexuality. We can't expect the Department of Education to do it all.
	I have no concrete suggestions on how this "safer sex" aspect of AIDS education could be made compulsory, but the situation clearly warrants more than a printed handout at registration time. AIDS education for students needs to address proper choice & use of condoms.

EDUCATION
Target Audiences
At-Risk or Hard-to-Reach Individuals

Street people, street kids	Prevention programs need to target runaways, school dropouts & drug users, street kids, the emotionally vulnerable, prisoners & teens of both sexes who prostitute. Prevention of AIDS in babies will depend partly on our success in reaching these groups.
	I believe there is a need for social "street workers" (non-religious) to get AIDS information to the kids not in school. I believe such a program was undertaken in British Columbia to reach gay hookers.
Street people, prostitutes	Working women also need to know explicit information such as the necessity of using latex condoms with water based lubricants if lubricants are desired. They also need to know that spermicides act as an extra protection against the AIDS virus.
	We believe that condoms should be distributed free to women working the streets. This would be an expression of support and good faith toward the women by the government, and would acknowledge their economic disadvantage and hardship.

An education campaign should educate customers of prostitutes about how to use condoms and the need to respect the use of condoms by the women whose sexual services they purchase.

With respect to working women who are IV drug users, studies show that education & free distribution of bleach solutions which sterilizes needles & kills the virus have been successful strategies.

Heterosexuals with multiple partners (including serial monogamy)

I would like to advocate an advertising campaign for the interior entrances of any/all bars or licensed premises & provincial liquor stores with the general idea: Don't drink & have sex with someone new. Your intelligence is hampered & you are careless.

PWA/HIV +

The type of education required by PWAs and HIV + persons is education about the reality of what AIDS will do to him/her. The emotional, physical and financial well-being of PWAs depends on how well we educate them.

The need for a comprehensive education program for PWAs is overwhelming. Each issue and problem needs to be identified and discussed in detail with the PWA and for every PWA the issues and problems will be unique.

Given the fear and uncertainty associated with AIDS, achieving a level of trust with PWAs may be difficult. Education programs developed and delivered by PWAs for PWAs will be more readily accepted, hence, a greater impact than efforts by outside agencies.

Funding should be made available to PWA groups for grassroots educational programs set up and administered by PWAs.

People With Aids recommend that all HIV-infected persons: engage in low-risk sexual behavior.

EDUCATION
Target Audiences
Workplace

Education re AIDS

Foster peer education in the workplace rather than bringing in outside specialists.

The government should initiate an AIDS ed. program that fully informs workers about risks of contracting HIV in the workplace. This education program must also inform workers of whether they have the right to refuse to work with a person who is HIV +, etc.

	Confidentiality is being recommended. There are precautions to be exercised in cases of AIDS. Do we, as a school board, act as if all students, teachers and other staff have AIDS?
	We should provide employees with information to protect themselves while away from the workplace. There is sufficient evidence that AIDS is a lifestyle disease which is sexually transmitted or transmitted during parenteral drug abuse with shared supplies
	Social service and other government agencies must take responsibility for ensuring that their employees have accurate information about AIDS. We have learned that in a local C.E.C., employees handling a PWAs dossier routinely seal the papers in a plastic envelope.
Employment policy	Each workplace must develop a set of guidelines to be followed for infection control.
Employment policy	There should be in-service training, continuing education programs for professionals (educators, law-makers, medics, clergy, etc.).
	Task Force should develop standard guidelines for infection control to be used as a model and adapted by Health & Safety Committees to each workplace.
	The government should adopt a policy requiring companies or agencies contracting with or receiving assistance from the government to implement employment policies with the same aim as government AIDS employment policies.
EDUCATION Target Audiences Care Givers	
Medical	The province, in cooperation with the Nova Scotia Medical Society must embark on a program to train physicians for pre- and post-test counselling and to assist in providing support services.
	N.S. Health Records Association suggests physicians in private, family and walk-in practices/clinics, dentists, & all others who access health data adopt policies & procedures to help educate & guide staff where the issue of release of information is concerned
CARE OF PERSONS Health Care	
Hospital	In time we will need special treatment centres and wards in hospitals devoted to HIV+ and

AIDS patients and eventually we may need hospital facilities for those in the final stages of their illness.

Hospital

Consolidation of services is needed so that a person may have access to all the various services available, both within the institutional setting and in the community, with a minimum of stress.

The tertiary care of patients with HIV infection should continue to be carried out at the Victoria General Hospital. This should include a special allocation for the funding of AZT. Currently the cost of this medication is $1000.00/patient/month.

A regional health care system for the care of PWAs should be developed. Not all patients with AIDS need the tertiary care facilities of the Victoria General Hospital. Now that our team has considerable experience with HIV, we can begin to teach others.

Funding agencies will have to remain sensitive to the financial requirements of hospitals as we respond to the diagnostic, treatment and caring needs of AIDS patients.

More emphasis should be placed by the medical community on the importance of rest, nutrition, relaxation therapy, stress management, visualization therapy and numerous other alternate therapies.

We support the use of experimental drugs. The risk of using these drugs often seems insignificant in contrast to the perceived benefits. These drugs often are the only hope for PWAs, and to deny PWAs their possible benefits seems callous.

Hospital

We recommend that Health Care Professionals treat people with AIDS as whole people, and address psychological issues as well biophysical ones.

We recommend that Health Care Professionals: Address the question of sexuality in people with AIDS, specifically, sensitive, of people with AIDS in particular.

Blood and body fluid precautions

AIDS does not differ from any other illness in that its victims and those close to them need & usually want spiritual support. The need for such support may vary in nature & degree during the course of the illness. It is, in all probability, long-term.

There should be one standard of practice for all health care situations. Universal Blood & Body Fluid Precautions are guidelines for practice

	sufficiently flexible to allow for professional judgment & decision making.
	Universal precautions have been implemented on a limited basis in such areas as the Intensive Care Unit & Outpatient/Emergency where it has been determined there is greater potential for exposure to the virus.
	It is hospital policy that only the caregiver should know the identity of AIDS patients and that all support staff should know is that blood and body fluid precautions are in effect. These precautions are used for any infectious disease.
Hospices	Begin site selection process now for special care facility (due to length of time required to develop such a facility).
Hospices	A six-bed residence be established (four resident, one transient and one hospice), with office space for MACAIDS and assistance from CARA with details in the areas of housing, program, staff and fund raising.
Home care	Multi-disciplinary resource team responsible for care & well-being of children with AIDS in the home, school and community, including medical treatment, sanitary procedure implementation and education, and care for care-givers.
	Families of AIDS patients need to be informed that in some cases the patient can be cared for at home. This will depend upon the particular disease with which they may have become terminally ill.
	Given the lack of abundance of V.O.N., Home Care, etc. services in the valley area, there may be a perceived need to hospitalize the AIDS patient for a greater portion of his illness than necessary.
	If the incidence of the disease increases, there is concern that already scarce resources will be further strained to the disadvantage of both PWAs & the general public. Hostels, hospitals or units working with acute care hospitals may be better.
	An unsolved problem remains establishing minimum housing requirements vis-a-vis one's basic needs. Communal housing may present problems for the PWAs in that they risk being exposed to infections from other residents which they are unable to fight off.

Research Clinical	Commitment to ongoing research for a vaccine and cure for AIDS. We feel that every effort should be made to encourage regional centres to increase their expertise regarding the diagnosis and treatment of PWA/HIV + s. A full time nurse co-ordinator is required to assist with the AZT program, including data collection and to coordinate the follow-up of patients with HIV who are in other hospitals in the province. Funds should be available for projects such as a retrospective study of Pneumocystis carinii and its unique aspects in Nova Scotia. With this and other projects which follow, a full-time research nurse, a data entry person & a lab technician are needed. Study the emotional impact of needlestick injuries at various hospitals in the province. Evaluate new diagnostic kits that come on the market. Additional resources are required so that the research aspects of HIV infection can be carried on in conjunction with the routine aspects of the laboratory diagnosis of this infection.
Research Epidemiology	Establish a Nova Scotian AIDS Research Centre. It is essential to continue to support and fund research into the causes and cures and the psychological impact of AIDS.
Research Epidemiology	Study seroprevalence of and attitudes towards HIV infections among Maritime prostitutes. We would like to study attitudes towards AIDS and HIV infections among university students and among a selected sample of the general population in Nova Scotia. The Government of Canada should have the responsibility of finding a cure, education should be a Federal/Provincial responsibility, and treatment should rest with the province.
Palliative Care	Palliative care should be encouraged, as well as support services for families and loved ones who are experiencing emotional, economic and social hardships during this period.
Dental	Although the majority of HIV + & AIDS patients can be treated safely in the dental office, there are both practice circumstances and disease related complications which may pose obstacles.

	Therefore care units in hospitals and like institutions are required.

CARE OF PERSONS
Psychological Support

Counselling for newly diagnosed carriers	If voluntary, anonymous testing is initiated, comprehensive, well-informed, compassionate counselling MUST be provided for persons who have undergone HIV antibody testing.
Counselling for newly diagnosed carriers	The March 4 Journal of the American Medical Association reports a higher suicide rate among people told they are carrying the infection, yet there has not been much emphasis on comprehensive, well-informed, compassionate counselling.
Continuing counselling for carriers	Some of the problems PWAs face are: fear of rejection, discrimination and loneliness ("Am I going to die alone?") despondency ("Is my life worth living?") anger ("Why has this happened to me?").
Counselling for family of carriers	The government consider a province-wide policy of appropriate support in view of increased emotional, financial and physical demands placed on caregivers in the pediatric foster care setting, and offer support services accordingly.
Counselling for family of carriers	A recruitment process is needed to discover foster families who are prepared to deal with the AIDS child's special needs. Since AIDS children should be placed in homes with older children to minimize the risk of infections some homes must be screened out
Counselling for family of carriers	Foster parents of children with AIDS need psychological counselling and guidance for assistance with the stress of caring for a child who is terminally ill and preparatory grief work.

CARE OF PERSONS
Social Services

Financial assistance/income support	Government should be willing to pay family support, retraining and relocating costs to any worker who must cease his current work due to HIV-conversion of any risk factor. Such should occur for work changes due to ANY incurable infectious disease. PWAs should qualify for long-term assistance under the provincial Family Benefits Program, and full access to disability benefits and drug cards should be guaranteed. The government must give clear direction to the 66 municipalities in Nova Scotia regarding the provision of municipal social assistance in cases

where HIV+ persons, homosexuals or those suspected of being homosexual lose their jobs or can't find work.

Counselling for HIV+ persons should include personal finance assessment. The PWA will need advice of someone familiar with government and social service agencies to determine programs/ eligibility for uninterrupted income should he/she become more seriously ill.

Those who work within the social assistance system may find it hard to comprehend how a person applying for assistance has difficulty accessing the system. For someone who is 40 years old and never relied on others for financial help the task is difficult.

Financial assistance/income support

Persons applying for social assistance for the first time will be reticent and insecure, but they will need support as they may not have resources to support themselves given their young age and difficultly in maintaining a job.

Both municipal and provincial social service agencies, and federal government programs such as U.I., C.P.P., etc, must take effort to familiar themselves with the circumstances involved in AIDS diagnosis. Presently, many people are being missed by the system.

Coordination of funding levels between various social services agencies responsible for housing to provide minimum housing standards when a person moves from the care of one agency to another remains an unsolved problem.

One unsolved problem that remains is to ensure that funds continue to be available to persons who are hospitalized, so that they need not be homeless after being discharged from hospital.

Residential care

The government of Nova Scotia needs to make plans for placement of AIDS children & teenagers so they do not stay in costly hospital beds when they do not need to do so. Placement in a facility or foster home in which a special fee is paid may be cheaper.

The government will need to provide leadership in the provision of specialized day care centres, home child care, respite care, small community based congregate facilities and non-traditional family placements.

Residential care

Medical care for victims requiring long term care. Consideration should be given if care is provided

	other than in an acute care hospital and the costs be paid for completely through the MSI program.
Advocacy services	PWAs' ability to cope with matters of employment, accommodation, finances, and legal concerns, decrease as the problems become more intertwined. Being in contact with the appropriate support agencies is not enough as various agencies work in isolation.
Role of Voluntary/Community Agencies	
Role of Agencies	Volunteer agencies have the ability to gain the confidence and trust of those we are trying most to reach. Volunteer agencies provide essential support services right in the community in a non-medical, informal setting. For persons who spend a significant portion of their time in hospitals, clinics, labs, etc., such efforts bring a sense of normality.
Role of Agencies	Since volunteer organizations are at arm's length from government, the organization can voice concerns affecting the well-being of patients/ persons. It can help accelerate government responses to pressing issues and can advocate on behalf of PWAs. MACAIDS and other volunteer organizations are a cost effective option in terms of AIDS education and support programs however, in order to continue effectively, a commitment for adequate financial support must come from the government.
Role of Agencies	We recommend that People With AIDS: Be involved in every level in decision-making and specifically serve on the boards of directors of provider organizations.
LEGAL/POLICY Confidentiality	
Need to know	Test results should be available only to the patient and family physician. Government should ensure confidentiality for PWAs & those HIV+. Confidentiality should only be broken in cases of willful endangerment. The purpose of reporting in Nova Scotia (tracking the disease) has been lost because of the fear of reporting. Those possibly infected are not being tested, on advice from some doctors.

	The Hospitals Act and the Health Act do not provide any meaningful prohibition against breaches of confidentiality with respect to such information being released by the myriad of people who would have legitimate access to such information.
	The confidentiality surrounding results of testing be improved immediately & drastically. Allowing slippage in the system inhibits people from being tested and makes it easier for the general public to engage in hysterical & discriminatory behaviour.
Need to know	The main concern in the hospital is the unknown HIV+ patient. To address this concern, we have coordinated, through our Infection Control Nurse, for in-services sessions for all staff, both clinical and non-clinical to be included in these sessions.
	Regarding employees in a hospital setting, what is reasonable risk?
	An area of potential difficulty may be with the Occupational Health & Safety Act & the employee's refusal to be exposed to the potential of becoming infected.
	There are too many instances in N.S. where test results have been leaked. While many of these leaks have not come the Department of Health, they have come from within the health care system. Most people don't distinguish between the two. A breach is a breach.
Penalities for breach	Legislation should be introduced to protect patients from wrongful, by lay persons, by making such disclosure subject to criminal prosecution with a significant mandatory penalty of say - one month in prison.
Legislation for protecting confidentiality	School Board shall maintain confidentiality of identity of person having contracted HIV or AIDS.
	People caring for chronically infective patients, including HIV+ patients, should have the right to know about the specific situation, including HIV positivity.
Legislation for protecting confidentiality	The Department of Health should report chronically infective workers, including HIV+ workers, to the appropriate control e.g.: Medical Licensing Board, hospital medical advisory committee (for MDs), hospital director of nursing (RNs & CNAs) etc.

Laboratory technologists should have the right to know when they are dealing with HIV infected specimens.

Should confidentiality be upheld when a doctor knows someone is being married or is marrying someone with the virus?

The Nova Scotia Family and Child Welfare Association recommends appropriate legislation be developed or amended to assist public agencies in carrying out their responsibilities regarding the needs of children and teenagers who test HIV seropositive.

Legislation should be introduced immediately requiring hospital officials to clearly mark the body of a person who has died of AIDS by sticking a label to the body using the words "INFECTIOUS DISEASE" in bold print at least 2" in height.

If a person with AIDS dies outside a hospital then the attending physician should be required to advise the embalmer that the person has died of an infectious disease.

Could medic alert bracelets assist those in the medical/ambulance field? It may not have to say AIDS, but could be coded.

Legislation for protecting confidentiality

The health care team cannot begin to meet the care requirements of patients with AIDS if they are not informed as per the Medical Guidelines for HIV Screening (N.S. Department of Health, Oct. 1987).

Not only must confidentiality be assured, it must be known to be assured.

Teachers have an obligation to make a referral of known or suspected HIV cases.

All workers who have access to medical files must be legally and ethically bound to honor and uphold rules regarding confidentiality.

Public disclosure

Patients should have the right to know if their doctor is HIV +.

Care provider status

A patient contracting HIV from a Doctor should sue both the Doctor (or his estate) and the hospital that knowingly allowed him to continue to practice.

We believe legislation should be introduced requiring physicians & hospital authorities to notify ambulance personnel when a patient who

	has AIDS is being transported by ambulance. Knowing that he/she had an infectious disease would allow for precautions.
LEGAL/POLICY Testing	
Reporting	Because many people who have participated in high-risk behavior are afraid of having their confidentiality breached, they avoid being tested. Voluntary testing is important for statistical purposes, therefore it is necessary to reassure confidentiality.
Contact tracing	Reportable diseases, including HIV positivity, should be followed up and contacts traced by the Department of Health. The individual doctor should not be the contact tracer.
Mandatory reporting	N.S. Department of Health develop a system of anonymous testing for HIV similar to that in use by the AIDS committee of Toronto.
	The health and assessment of HIV+ individuals should be monitored with a frequency that will assure the interests of the School Board, in protecting the health and safety of all students and staff, is supported.
	My concern is that there needs to be some way of monitoring those who have the privilege of confidentiality in order to make sure there is no abusing of that privilege. This may happen if a person refuses to make the necessary changes in lifestyle.
Informed consent and counselling	Testing should not occur without a patient's knowledge.
	AIDS testing of a patient without consent is neither illegal nor unethical and may well represent the only serious hope of limiting the spread of this condition.
Informed consent and counselling	Take practical measures to halt the spread of AIDS, as per Public Health (Control of Disease) Act 1984 (England). . . .allow orders to be made for patients who have AIDS to be medically examined & for AIDS patients to be removed to hospital & detained.
	Testing carried out with prior knowledge should only be done after intensive counselling and, in the event of positive results, this counselling should be ongoing.

	Adequate funding should be provided to ensure that the necessary resources are available for counselling.
Mandatory testing	Mandatory testing is potentially very expensive (as it has to be repeated regularly) and serves no purpose in stopping the spread of the disease.
	Screening of selected socio-professional groups (e.g. pilots, train drivers – those responsible for the lives of others) may be appropriate in order to avert the risk of accidents and disasters of human origin.
	Continuing chronically infective conditions (including HIV) testing should be mandatory in doctors, nurses, lab technologists who collect blood, teachers, school cafeteria workers, school bus drivers, certain public transport workers, military personnel.
	All hospital admissions should be automatically tested for certain infectious conditions including HIV.
Mandatory testing	There should be federal authorization for public and private employers to utilize AIDS risk factor questionnaires & AIDS blood screening tests in hiring. Insurance companies must be permitted to utilize these means in selecting applicants.
	How about testing for AIDS prior to marriage? There are problems in doing this I know. How long before the wedding, etc.? Would people that have AIDS be allowed to marry?
	Attention focused on testing and quarantining gives the public a false sense of security about who is at risk.
	If it is necessary to adopt a policy of mandatory testing and identification there can be no exceptions. No individual or group can be singled out for special treatment or exclusion except with unfairness to others & detriment to the program.
	The school board has a right to request that an employee undergo a medical to ensure his/her ability to continue working without posing a health risk to others.
Quarantine	We conclude one chance in a million of contracting this fatal disease is too high a risk if it may be prevented. It may be prevented as demonstrated in the past with other diseases, by isolating the individuals, be they innocent or morally at fault.

Quarantine

When the idea of quarantine is proposed by people who wish to segregate one group of individuals from another, for reasons based only on fear or loathing, all members of a free society must be on their guard.

The Government must be prepared to restrict the freedom of movement of HIV and AIDS infected persons if, and only if, they do not voluntarily conform to non-threatening behavior.

LEGAL/POLICY
Human Rights
HIV+

Employment School

Every reasonable effort to provide a suitable arrangement should be made if a student's or employee's condition necessitates special consideration.

All school boards should be required to develop policies relating to AIDS, using guidelines provided by the Provincial Government.

Can we, as a school board, compel students to attend a class where parents perceive the teacher to be a danger and immoral?

Decisions regarding alternative instruction outside the school for infected students should be made on a case-by-case basis in consultation with parents and family physician.

The Superintendent shall, on behalf of the Board and the appropriate professional or union representative – i.e. N.S.T.U., C.U.P.E., etc., in consultation with the principal, administrator or supervisor, attempt to work out procedures for benefits.

Employment Non-school

Persons with HIV+, ARC or AIDS should be allowed to continue to work without being discriminated against in any way.

Government must require hospitals to provide professional and compassionate medical care without discriminating against or ostracizing AIDS patients.

A person testing HIV+ or having AIDS should be allowed to work and continue in work or in school until his or her infectability becomes a threat to other people, as determined by the local Medical Officer of Health and the person's private physician.

If a person is judged to be a risk to others, that person should either be employed in an area where there is no contact or be given appropriate time off work.

Doctors, nurses, laboratory technologists and some x-ray technologists who deal "hands-on" with patients should be HIV-.

Recommend to the Nova Scotia School Board Association that they establish across the province a uniform policy on AIDS similar to the one adopted by the Halifax District School Board. It is fair, humane, realistic and based on most current medical information.

Parents have a right under Section 74 of the Education Act to have their children placed in a classroom free of fear and taught by a teacher they perceive as exhibiting Christian morality. Many people, clergy included, look upon homosexuality as immoral.

Employment Non-school

We recommend that All People: Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones, our community and our peers.

Housing

Given the situation of HIV-positive persons, who are working and are basically asymptomatic, being asked to vacate rented accommodation if their HIV status becomes known. We recommend legislation affecting this area be clarified to prevent its occurrence.

Provision of services

Government should safeguard the rights of people with AIDS and people testing HIV+ with respect to pension plans, insurance coverage and continuing professional medical care.

Task Force should recommend that PWAs or with ARC, HIV+ and persons perceived to be members of high risk groups be considered to have a disability for purposes of the application of the Nova Scotia Human Rights Act.

People With AIDS recommend that All People: Recognize that PWAs and HIV+ persons are individuals and treat us accordingly.

People With AIDS have the right: To live as full and satisfying sexual and emotional lives as anyone else.

People With AIDS have the right: To full explanation of medical procedures and risks,to choose/refuse their treatment modalities, to refuse to participate in research without jeopar-

	dizing their treatment and to make informed decisions about their lives.
Provision of services	People With AIDS have the right: to privacy, to confidentiality, of medical records, to human respect, and to choose who their significant others are. People With AIDS have the right: to live useful productive lives as part of the community.
Sexual orientation	The Anglican Church of Canada supports the inclusion of provision in the Human Rights Code for the protection against discrimination on the basis of one's sexual orientation. The Task Force should begin its report with a clear statement regarding the value and rights of gay and lesbian people and that it insist that part of all education programs be aimed at dislodging homophobia. If you're not a homosexual, and you got AIDS, how would you be able to prove you are not gay? AIDS is not an issue just for students, AIDS is not an issue just for governments, it is an issue for every sector and every participant in society. It is an issue by which one could well measure the compassion and humanness of society itself.
Legislation Regarding Infection Control Procedures for Specific Workplaces	
Legislation for Specific Workplaces	The Department of Health and all local Boards of Health should have registration and regulations to control infections in acupuncture, tatooing, ear-piercing and electrolysis.
Liability	Failure of a school system to warn a teacher who can become pregnant of the risk posed by an HIV + student could lead to an undefendable suit when she delivers a CMV baby.
Morality	AIDS is a public health issue and not a morality issue. As a pastor, I am extremely disturbed to hear clergymen in the name of compassion, justify homosexual conduct and regard those who practice and contact AIDS as "victims". Such ministers are betraying their trust before God. There must be a federal and provincial crackdown on pornography soliciting persons for high-risk sexual activities.

There must be a crackdown on massage parlors and vice rings promoting anonymous heterosexual promiscuity.

I believe that keeping somebody in the work force needs to be looked at from the moral issue as well as from the health issue.

Prisons

Some adults blame prostitutes in Halifax for AIDS. Some were concerned about occupational hazards of working with individuals. Some women had real concerns about conjugal visits to partners in penitentiaries.

We are starting to see persons that will soon be released from correctional institutions who, because of their illness, are not welcome to return to their families and whom the Parole Board is unable to place in alternative settings.

Philosophy

When an HIV+ or AIDS patient is treated there is inevitably infectious waste, waste that requires safe disposal. We encourage the development and implementation of a specific contaminated waste disposal system province wide, accessible to all.

There must be universal access to equal quality care, not just in word, but in deed, not just in administrative policy, but in service. There must be ongoing evaluation of services which are publicly funded to ensure that kind of care.

Fear of lack of confidentiality may prevent applications for assistance from PWAs, seropositive persons and uninfected homosexuals who have lost employment from seeking help.

Education and support are certainly not mutually exclusive issues. The psychological stress for PWAs & HIV+s will be significantly reduced once communities, through education, see AIDS as everyone's concern & move beyond fear to acceptance of those affected.

Contact tracing suffers from the same problems as mandatory testing and quarantine with respect to identifying carriers of the virus. It also provides opportunities for breaches of confidentiality and invasion of privacy.

At present a positive ELISA test for HIV infection is reported to the Department of Health since this is a screening test. Most of the positives are false positives, thus a HIV test result should be reported only if a confirmatory test is positive.

Prostitutes from West Germany where prostitution is legal have reported that because they were required to test for antibodies to AIDS virus on a regular basis, customers were refusing to use condoms.

Compassion dictates that anyone who suffers will be afforded the best treatment of which society is capable. Whatever treatment is necessary & available must be offered as it is in the case of any other illness.

The fears & anxieties of AIDS sufferers, their families and friends must be addressed. The issues of life and death must be dealt with as well as feelings of denial, anger & grief. Clearly the churches have a significant role to play.

Massive public education & the establishment of new services/programs costs money. We must consider the long term effects of costs vs. benefits and future health care/medical costs of our young population.

Hospitals do not have the luxury of engaging in emotional or rhetorical debates over personal or community values but must cope with the consequences of treating patients with infectious diseases and potentially lethal consequences.

We do not have direction on how to deal with the moral, legal & ethical issues. We do not have any direction on how to maintain public safety, yet respect the privacy of the patient. We do not know yet how to deal with the human element, only the disease.

AIDS is in the heterosexual community & it is not only spread through sexual contact. Teaching prevention does not promote sleeping around or drug use. It is one of the best ways to prevent these things because it will alert people to the danger.

In my Phys. Ed. theory class, a student asked a question about AIDS. Our teacher was not allowed to answer it because of school board policy.

Within the first few years of the AIDS syndrome being present in the gay communities of North America the opportunity to contain the virus through educating the general public was lost. We are not innocent bystanders to the growth of this disease.

How come I have to learn about AIDS – I'm not a homosexual?

How many years does it take for AIDS to kill a person?

Why isn't it talked about, prevention I mean, on television?

What are my chances of me getting it, my first time?

Many individuals are concerned that by using their names in the testing process, they will be identified with a high risk group.

Should an individual test positive, he or she fears the repercussions, should they be identified through the different testing channels such as the doctor's office, the hospital, the laboratory or the Department of Health.

Do we have to worry about AIDS in Kings County?

Some physicians & other professionals are either not recommending the HIV test or even counselling against it because of its unreliability or due to the reporting system. How accurate can the estimate of cases be if this is the reason for reporting?

SUNS recognized the sensitive nature of AIDS and related issues but SUNS is also aware that THERE IS NO MORAL OR SOCIAL ISSUE GREATER THAN LIFE ITSELF.

Copies of written submissions, including names of presenters, is available through the Nova Scotia Task Force on AIDS, P.O. Box 488, Halifax, Nova Scotia B3J 2R8.

Listing of Persons Interviewed or Consulted During Preparation of Report of the Nova Scotia Task Force on AIDS

International

London:	Mr. Bernard Markel, Director AIDS Unit
	Mr. Simon Lawtin Smith, Assistant Director
	Dr. Robert Terrel, Public Relations
	Dr. Arthur Collindale, Director, Public Lab
	Professor Allan Gwynn, Researcher, Public Lab
	Ms. Susan Perle, Director, Health & Education Authority
	Mr. Rooney Amis, Asst. Librarian
	Ms. Jane McKesiek, Acting Manager, National AIDS Trust
	Mr. David Panter, Project Coordinator, AIDS Education Project
	Mr. Nick Patridge, Director, Terrence Higgins Trust
	Mr. Simon Walder, Associate Director, Terrence Higgins Trust
Edinburgh:	Mr. Martin J. Raymond, Director, Scottish Health Group
	Mr. Robert Mitchell, Director, Health Education Centre
Melbourne:	Mr. Phil Carswall, Program Manager, Victorian AIDS Council
	Mr. Bruce Parnell, Manager, Gay Mens Health Centre
	Mr. Toni Carger, Manager, Communicable Disease Centre
Canberra:	Mr. Ian Huhaupt, Acting Secretary of Department of Communicable Diseases and Director of AIDS Secretariat
Sydney:	Dr. Robin Taylor, Director of AIDS Education Bureau
	Mr. Kevin Donnelly, Director, Schools Directorate
Auckland:	Mr. Warren Linberg, Director, New Zealand AIDS Foundation
Wellington:	Dr. Karen Pouttisi, Chief Health Officer
	Ms. Bette Kill, Manager, Health Promotion Program
	Dr. John Stephenson, Manager, Health Protection

Canadian

Newfoundland:	Dr. Kevin Hogan, Director of Community Health, Department of Health
	Ms. Joan Casey, Home Economics Consultant, Curriculum Division, Department of Education.
	* Dr. Faith Stratton, Provincial Consultant of Disease Control and Epidemiology
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	Ms. Arlene Mamye, Homecare Co-ordinator, Department of Health and Social Services
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* **No interview, revised draft only.**

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Other:

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Ms. Margaret Duckett, Visiting Scholar, McGill Centre for Ethics and Law

Mr. Greg Smith, Executive Director, Federal Centre for AIDS

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Ms. Lyne Champoux, Communications Director, Canadian Association of Broadcasters

Rev. Bob Petite, Pastoral Care, Victoria General Hospital, Halifax

Dr. David Walters, Canadian Public Health Association

Dr. Tom Marrie, Victoria General Hospital, Halifax

Ms. Yvonne Lynch, Acting Head Nurse, Victoria General Hospital, Halifax

Dr. Walter Schlech, Victoria General Hospital, Halifax

Dr. Robert Frederickson, Family Physician

Mr. Bob Moody, Provincial Co-ordinator, Home Care Program

Mr. Stuart Brown, Director of Homemaker Services

Description of Video Presentation Prepared to Accompany Final Report of the Nova Scotia Task Force on AIDS

With assistance from Health and Welfare Canada, the Nova Scotia Task Force on AIDS was able to record on videotape the public meetings on AIDS it held throughout the province. This series of meetings was an unprecedented effort to hear the opinions of interested groups and members of the general public on AIDS and related policy issues.

The resulting videotapes represent a valuable and unique record of public worries, attitudes and suggestions concerning AIDS. They demonstrate Nova Scotians' deep level of concern about the disease, the compassion and consideration toward people who have been struck by AIDS which were an outstanding feature of the meetings, the careful consideration which professional groups have given to the problems associated with AIDS and the questions and suggestions of the general public.

This videotape has been utilized as the basis for a videotape production outlining the work and recommendations of the Task Force. It is hoped that in conjunction with another on the medical facts on AIDS, this videotape may be used to educate interested community groups on the challenge of AIDS and the suggested policy response in Nova Scotia. The videotapes provide a wealth of material for preparation of additional packages, summarizing the meetings and highlighting specific issues concerning the disease.

Listing of Papers Commissioned by the Task Force

1. *A Study of Attitudes and Beliefs About AIDS in Nova Scotia for the Nova Scotia Task Force on AIDS*
   – by Decima Research Limited

2. *The Influence of Victim and Respondent Characteristics on Attitudes towards AIDS: A Report to the Nova Scotia Task Force on AIDS*
   – by students from Mount Saint Vincent University

3.* *AIDS: In Search of a Public Policy Response*
   – by Dr. Barry Lesser

4.* *Public and Private Health and Care Services: Report to the Nova Scotia Task Force on AIDS*
   – by Dr. Lynn McIntyre

5. *Living with AIDS – The Reality*
   – by the Nova Scotia PWA Coalition

6.* *The Pastoral Care of Persons with AIDS: "Perfect Love Casts Out Fear"*
   – by Reverend Robert Petite

7.* *Teaching Children Hygienic Procedures to Reduce the Risk of Infection*
   – by Psychology Department, Izaak Walton Killam Children's Hospital

8.* *What the Provinces are Doing*
   – by Barbara Whitby

A copy of any of these papers will be available at cost through the Nova Scotia Advisory Commission on AIDS.

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* Published with limited distribution as part of a background package.

AIDS: In Search of a Public Policy Response

A Background Paper

submitted to

The Nova Scotia Task Force on AIDS

by

B. Lesser
Dalhousie University
and
The Institute for Research on Public Policy

August 1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

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AIDS: In Search of a Public PolicyResponse

A. Introduction

AIDS is not only a medical health issue, it is a societal issue. AIDS raises far-ranging and very significant social, cultural, legal, and ethical questions. As such, it is a major public policy issue. Indeed, it could be argued that it is one of the most significant public policy issues now confronting Canadian policy-makers and the people of Canada. Consider:

- the **pervasiveness** of AIDS – current WHO estimates predict that over the next 30 years, 15 million people in North America alone will be infected. Contrary to early impressions, it is a disease that can affect everyone – men, women and children; whites and non-whites; people of all countries. The disease knows no boundaries in terms of gender, colour, race or national origin.

- the **internationalization** of AIDS – AIDS has no geographical boundaries. It is a problem confronting every country and presently available responses to the crisis are equally interdependent amongst countries.

- the **moral/ethical issues** posed by AIDS – in part due to lack of understanding and misinformation by the public, in part due to uncertainty regarding some of the medical aspects of the disease, and in part due to a genuine conflict for many people with their own personal value system, AIDS has become a classic example of the trade-off between the rights of the individual and the rights of society. But there is a major question of whether this is a legitimate characterization. This may be the most significant moral problem of all posed by AIDS.

- the **uncertainty** surrounding AIDS – medical science has no absolute answers to AIDS. We know that there are no reported instances of transmission through casual contact but this is not a guarantee that transmission by casual contact is impossible or has not occurred. We know that a positive HIV antibody test usually means that the individual is a carrier of the virus but false positive results are possible and a negative test does not mean that the individual is not infected. We know that people with AIDS have HIV antibodies in their bloodstream but not everyone with HIV antibodies will contract AIDS. And so on. Amidst this uncertainty, how do we decide on appropriate actions to contain and control the disease?

- AIDS is **terminal** and **non-curable** – persons who suffer from AIDS will die. That is one thing we do know. It is a significant factor in explaining the fear and, at times, hysteria surrounding the disease. It is a significant factor in explaining the political pressure on governments to do something to contain/control the spread of AIDS. But does the end justify any means?

- the **complexity** of the issue – AIDS is not simply a medical problem. Its pervasiveness, terminal character, international character, moral character, etc. make it an issue which touches all aspects of our society.

- the **challenge** of AIDS is to maintain efforts to find a cure *but*, at the same time, not knowing how long such an effort may take or whether it will ever be successful, to address in a humane fashion, the social, economic and health-care needs of people with AIDS while also responding to the need of society to be protected. Public policy, however, should not be governed by hysteria. Individual rights, a cornerstone of a free democratic society, cannot be sacrificed without proper justification if the principles of such a society are to be preserved. It is the danger that this could happen, due to ignorance, uncertainty, fear, and simple irrationality, that makes our response to AIDS such a vital public policy issue.

This paper is concerned with

- identifying the social, cultural, legal and ethical issues posed by AIDS
- analyzing the substance of these issues
- exploring the policy options available to policy-makers
- examining models of the treatment of ethics in public policymaking as a guide to a discussion of how the public policy process can deal with AIDS.

A primary focus of the paper will be the rights of the individual versus the rights of society (and, as a corollary to this, the respective responsibilities of each). An important dimension of this question is the extent to which there is a real, versus a perceived, conflict between the two. One of the factors which is responsible for the complexity of the issue and its challenge is that it is such an emotionally-charged issue:

- people fear contracting the disease
- it is identified in the public mind with homosexuals and drug abusers.

People's fear of contracting the disease and the terminal nature of the disease, plus the social stigma which arises from the identification of AIDS with homosexuality and drug abuse, give rise to pressure on governments to contain and control carriers to protect society at large. Homophobia leads some to view AIDS as a form of moral retribution. At the very least, for many, it creates a climate of indifference to the rights of AIDS sufferers, lending support to an argument of the paramountcy of society rights over individual rights. Contributing to these positions is the fact that there is a tremendous amount of ignorance, misunderstanding and misinformation regarding AIDS in the minds of the public. There has been a veritable explosion of articles, news items, books, etc. on AIDS, much of it in a "popular" media form, full of mis-information and half-truths and, in some cases, of a deliberately sensationalizing nature. To date, it is these forums which have been the primary source of public information on AIDS. The result is a significant number of people who are grossly uninformed or misinformed about the nature of the disease, how it is spread, preventative measures, etc. There are many people who do not know the difference between a HIV antibody test and an AIDS test, or the difference between carriers and people who actually have the disease, or the meaning of a negative antibody test. Fuelled further by medical uncertainty and the perfectly natural and understandable fear of a terminal, non-curable disease, irrationality is the result.

Part of the complexity of the issue comes, however, not from ignorance, irrationality and uncertainty, but from a fundamental conflict between personal or collective ethical standards and some of the issues posed by AIDS. For example, a belief in the freedom of religion may conflict with a prescription of compulsory AIDS education or mandatory blood tests; a belief that drug use is ethically wrong and illegal, and therefore to be suppressed by government, may conflict with a prescription of dispensing free, sterile needles to drug addicts, insofar as this is seen as supporting illegal drug use; a belief that homosexuality is not consistent with principles of "Christian morality" may conflict with campaigns aimed at educating gay men and women on "safe" sexual practices. The argument here is not whether these personal ethical beliefs are correct in some objective sense but that, *given these beliefs*, the way in which different individuals react to different policy options available to government and/or the policies they prescribe for government cannot all be dismissed as irrational.

The issues, then, are important. The debate is pervasive and extremely complex. The debate is fuelled by fear, homophobia and views of drug abuse. It is fuelled by ignorance, irrationality and uncertainty. It is fuelled by those who believe in the paramountcy of individual rights and those who believe in the paramountcy of the collectivity. It is tempered by those who would seek a rational balance based on a considered analysis of the facts and the relative risks. It is the task of the policy-maker to be able to separate these views and pressures and act on a considered, rational basis, and not succumb to the pressures borne of fear, ignorance and irrationality. This is not an easy task but it is a necessary one.

B. Identification of Issues

The public policy issues posed by AIDS can be classified or categorized under four main headings:

- the workplace
- the health sector
- the community
- the polity (government).

Each of these represents an environment in which AIDS issues emerge. They are not mutually exclusive, as is evident from the listings below, although explicit repetition of issues has been minimized. In particular, every issue involves government insofar as all the issues listed are presented as public policy concerns. This overlap, in part, reflects a certain arbitrariness to the classification while, at the same time, underlining the interdependence of the elements in the debate. It demonstrates, as well, the different directions from which one can approach certain of the issues and, sometimes, the different views which this can create. What is perhaps most striking about this categorization of the issues is that it ties the issues to daily life – where we work and where we live, how we are governed and how we care for each other. It places the issues in a more tangible setting than would a more abstract discussion of ethics, or confidentiality or information flows. In the process, it also underlines the pervasiveness of the issues – there is no aspect of our daily lives which does not take place within or is not influenced by at least one of these four environments.

What then are the issues?

The Workplace

Workplace issues are those involving the terms and conditions of employment of AIDS persons. These include:

- the right of persons with AIDS (PWA) and AIDS virus carriers (HIV+s) to maintain their employment
- testing of employees
- testing of job applicants
- disclosure to employers
- disclosure to co-workers
- disclosure for unemployment insurance benefits
- rights of participation in employee benefit plans
- employment in jobs involving contact with the public or food and beverage industries
- work reassignment of PWA/HIV+s
- the right of co-workers to refuse to work with PWA/HIV+s
- discrimination against PWA/HIV+s in the workplace
- discrimination against workplace associates of PWA/HIV+s
- employer responsibility for AIDS education in the workplace.

The Health Sector

Health sector issues treated here involve ethical issues and decisions on level and type of care in terms of funding and regulation. Specifics of care options are not treated in detail.

- the right to treatment
- the right of individual health workers to refuse association
- the confidentiality of health records
- access to information by health researchers
- anonymous disclosure to public health authorities
- identified disclosure to public health authorities
- access of patients to health records/right to be informed
- testing without consent or knowledge
- blood donor screening

- contact tracing
- quarantine/isolation of PWA/HIV + s
- health workers testing positive to AIDS/HIV antibodies
- provision of care facilities
- counselling responsibilities of physicians/health care workers
- regulation of experimental drugs/treatments

The Community

The community environment, in the present context, relates to the terms and conditions affecting the position of PWA/HIV + s in interacting with their fellow citizens.

- teachers with AIDS or testing HIV +
- the right to attend school
- mandatory AIDS education in the schools
- compulsory AIDS education in the schools
- the right to keep children out of school because of the presence of AIDS carriers
- mandatory testing at a mass level for specific groups (homosexuals, prostitutes, prison inmates)
- family disclosure
- school disclosure
- public disclosure
- labelling of PWA/HIV + s
- individual responsibility for self-protection
- quarantine/isolation of PWA/HIV + s
- access to publicly sold services by PWA/HIV + s (including insurance)
- access to social services
- access to housing
- public education – funding and content

Government

Government in this context encompasses those specific issues involving the conduct of the public sector and certain recognized areas of specific government responsibility which do not otherwise fall within any of the other three categories.

- AIDS research support
- information needs
- disclosure requirements
- confidentiality of government records
- intra-governmental information access
- provision of social services
- testing as a condition for issue of a marriage licence
- mandatory testing of government employees
- mandatory testing of immigration applicants
- testing of international travellers
- denial of immigration to PWA/HIV + s
- denial of citizenship to PWA/HIV + s
- drug/treatment regulation
- enforcement of PWA/HIV + s rights (once decided upon)
- decision-making with uncertainty
- decision-making with dissensus
- decision-making for conflicting objectives (e.g. promoting safe [i.e., clean] drug use; compulsory education in schools; counselling for prostitutes).

Most of the issues listed in this four-part categorization, in fact, deal with or relate to one or more of three overarching themes:

- information – content, distribution and use
- the rights of PWA/HIV + s
- the protection of society.

Like the previous categorization, these are not mutually exclusive. One of the most compelling arguments for information distribution on PWA/HIV + s to third parties, for example, is the protection of other members of society. Similarly, the rights of PWA/HIV + s and the protection of society clearly overlap in the sense that they are in conflict with one another and will remain so at least until a cure for AIDS is found.

Before turning to a fuller discussion of all these issues, let us first examine some of the "facts" about AIDS.

C. Some Facts About AIDS*

AIDS stands for Acquired Immune Deficiency Syndrome. It is the most extreme form of an infection caused by a virus known as the human immunodeficiency virus (HIV) or alternately, HTLV-III (Human T-Lymphotropic Virus Type III), LAV (Lymphadenopathy Associated Virus), or simply, the AIDS virus.

The AIDS virus impairs the immune system of an infected person, damaging their capacity to fight other diseases. It does this by attacking certain white blood cells after entering the blood stream. In response to the virus, the body produces antibodies to the virus. These are detectable by a blood test known as the ELISA Test between two weeks and three months after infection.

Degrees of Infection

A person who is infected with the AIDS virus will fall into one of three categories, representing progressive stages of the infection. These stages need not occur in any particular order, however, nor will all stages necessarily occur in a particular individual. Moreover, the time span for progression of the disease may vary from a few months to years. Scientists in the U.S. predict that 25 to 50 per cent of those infected with the AIDS virus will eventually develop AIDS. Some European scientists predict that anyone infected with the virus will develop AIDS *eventually*.

The three categories of AIDS-infected persons are:

- Persons infected with the virus but who display no physical symptoms of illness.
- Persons infected with the virus and who display a specific set of clinical symptoms. Such symptoms may include a loss of appetite, weight loss, fever, night sweats, skin rashes, diarrhea, tiredness, lack of resistance to infection, or swollen lymph nodes. Such symptoms may be associated with diseases other than AIDS but several at once which persist and are accompanied by a positive test for the AIDS virus will usually be diagnosed as AIDS-Related Complex (ARC). ARC sufferers will not usually require hospitalization and will be able to carry out most/all of the daily functions of life, albeit with perhaps some interruptions. A person may also exhibit some of these symptoms in mild form, in which case an ARC diagnosis may not be made. Some researchers identify this as a separate stage of the disease.
- Persons infected with the virus who develop opportunistic infections or cancers which may be fatal. Brain injury, also potentially fatal, may also develop. In this stage, the immune system has become sufficiently damaged that it can no longer resist these life-

threatening situations. This degeneration is almost certain to eventually prove fatal. It is in this stage that the infected individual is considered to have AIDS.

It is important to recognize that persons in all three categories are carriers of the virus and, therefore, capable of passing it on to others.

Transmission

The AIDS virus may be transmitted by four *known* ways:

- through sexual contact with an infected person
- through sharing contaminated needles or syringes
- through transfusion of infected blood or blood products
- from an infected mother to an infant in the womb, at birth or during breast-feeding.

Aids is a blood-borne disease and is found in body fluids, including the blood, semen or vaginal fluid, saliva, tears, feces and urine. In these latter four cases, however, concentrations of the virus are very low and the best available medical opinion *at present* considers it impossible to transmit the virus through contact with any of these substances. *There is no known case of someone contracting the virus through casual contact with an infected individual.*

Thus the virus is not considered to be transmissible through, for example, eating or drinking from common utensils or from swimming pools, toilet seats, handshakes, or the use of common facilities such as telephones. AIDS is not an air-borne disease. In fact, the virus will die if exposed to the air. Thus it cannot be transmitted by coughing and sneezing. There is no evidence to even remotely suggest that AIDS can be carried by animals or transmitted by biting insects such as mosquitoes. In fact, there are several reasons for virtual certainty that mosquitoes cannot carry and transmit the AIDS virus.

It is not known at this time whether other conditions or contributing factors must be present to trigger the disease in addition to the presence of the virus. It has been established that the risk of infection increases according to the number of sexual partners one has, whether male or female. This does not mean, however, that repeated exposure is necessary to be infected; rather it is the case that the more sexual partners one has, the greater the probability of at least one of them having the virus and transmitting it – once may be enough.

Detection

The most common means of detecting the presence of the virus is by means of an antibody test, commonly referred to as the ELISA test. The presence of antibodies is generally assumed to mean that the virus is present. Two caveats, however, are in order regarding this test:

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* Much of the information contained in this section is based on James D. Greig, *AIDS: What Every Responsible Canadians Should Know*, (Toronto: Toronto Sun Publishing and The Canadian Public Health Association, 1987

- A negative antibody test does not necessarily mean the individual is not infected with the virus. A test performed too soon following exposure may fail to reveal antibodies because the body has not had time to manufacture them. It could take from three weeks to three months for antibodies to develop. There may also be instances in which the body will not develop antibodies at all but where the virus is present.

- A positive antibody test does not necessarily mean that the virus is present. Studies involving a direct test for the virus amongst persons testing positive for the antibodies have shown that only 60 to 80 per cent of antibody-positive individuals also have the virus in a detectable form. One hypothesis for explaining this is that the virus may, in fact, be sequestered in a non-easily detectable part of the body. Another hypothesis is that some individuals have been able to rid themselves of the virus.

Despite the uncertainty or, perhaps, because of the uncertainty, antibody-positive individuals are assumed to be carriers of the virus. Antibody-negative individuals, however, are not assumed to be free of the virus. The antibody test will usually be followed by a confirmatory test to reduce the probability of a mistake in the ELISA test.

In addition to the antibody test, a direct test for the AIDS virus itself is also possible, although not yet widely so. This test is called the antigen captive assay. It can detect the virus in early stages of exposure before antibodies have developed. It can also be used to confirm the antibody test *if both are positive* but not if the virus test is negative while the antibody test is positive. For high-risk individuals, the virus test can also be used to confirm a negative antibody test. The problem, however, is that this test is still essentially a tool for researchers, versus normal diagnostic work. It is limited in availability, expensive and time-consuming. And, *by itself*, it may be no more conclusive than the antibody test.

Who is At Risk?

Anyone can be infected. In this sense everyone is at risk. AIDS knows no boundaries in terms of gender, age, sexual preferences, colour, or geography. As such, everyone is potentially at risk. Having said this, certain populations have clearly been shown, *empirically*, to be more at risk than the general population:

- homosexual or bisexual men
- intravenous drug users who share needles
- people who have had multiple transfusions of blood or blood products in the past.
- heterosexual partners of infected individuals
- infants of women who were infected during pregnancy or breast-feeding
- persons having sexual intercourse with someone from an area where AIDS is endemic.

In the case of blood transfusions, screening tests for AIDS (the antibody test) now used by the Red Cross on all donated blood in Canada have made this means of infection virtually impossible. This screening procedure has been in effect since November 1985. In addition, hemophiliacs now receive only blood products which have been heat-treated so as to inactivate the virus should it be present. For regular blood transfusions, there may be some residual

chance of infection given the less than 100 per cent certainty of a negative antibody test but the weight of evidence favours an assumption that transfusions now are an infection-safe procedure. Screening also is now routine for all donated tissues, organs and sperm. A recipient of an unscreened donation could be at risk of infection.

At a more general level, transmission is possible in any situation where a person may come into contact with the blood of an infected person and ingest this blood into their own bloodstream. Both conditions, however, must be met for infection to occur. In other words, except for the four methods of transmission noted previously, *infection is not easy*. In any situation where body fluid spills may occur, normal safe hygiene practices (clean equipment, protection of cuts and sores, washing, disinfection of potentially contaminated areas, use of disposable equipment, etc.) recommended to control many kinds of viral infection should also suffice to protect against AIDS.

Summary

This discussion of "facts" about AIDS reveals a number of things relevant to our subsequent consideration of AIDS-related public policy issues:

- Based on the best available medical evidence at present, there is no reason to believe that AIDS can be transmitted by casual contact.
- Based on the best available medical evidence at present, there are only four means of transmission of the virus, as previously listed.
- Persons at risk are only those involved in one of these four practices.
- Negative antibody tests do not mean the virus is not present.
- Positive antibody tests, while not conclusive evidence the virus is present, must be treated as if this were the case.
- Everyone who has the virus will not necessarily contract full-blown AIDS, although medical opinion is divided on this issue.

With these conclusions in mind, let us return to our examination of the issues.

D. Analysis of the Issues

The facts about AIDS just reviewed strongly indicate that many of the fears about public safety are *unjustified* and thus arguments in favour of legal constraints on the rights of infected individuals or high-risk individuals are, *in most cases*, also unjustified.

This is not an argument that individual rights are necessarily paramount over societal rights. Rather, it is an argument that the supposed conflict is, in fact, not a real one because societal rights are not at threat to the extent that many presume them to be. In other words, if we accept that individual rights should not be compromised unless there is a clear and demonstrated danger or threat of loss to others, then many of the potential limitations which might be imposed on PWA/HIV+s have no justification on the grounds of ethical choice between the rights of the individual and the rights of society.

Which issues are involved in this?

- the debate over the public's right to know
- the debate over quarantine/isolation or visible identification of PWA/HIV+s
- the debate over PWA/HIV+s in the workplace, schools, and other public environments
- the debate over mandatory testing

Before examining each of these in more detail, it is useful to note some additional arguments relevant to the discussion:

- the ethical questions posed by AIDS-related policy issues typically are not absolutes. It is not a case of good versus evil or truth versus lie or right versus wrong. It is a matter of relatives, of seeking a balance, first with the facts as they are presently known and second, between the rights of the one and the rights of the many.

- ethical questions have two sides—they involve not only rights but responsibilities. Society wants the right of protection from AIDS but society also has a responsibility to care for people with AIDS. PWA/HIV+s want the right to enjoy all the rights of citizenship but they also have the responsibility to practise those rights in a socially responsible manner. And so on.

- the reality of the public danger from casual contact with PWA/HIV+s does not alter the perception of danger. It is not enough for government to conclude that the danger is not real and therefore to do nothing. Government clearly has a residual (but non-trivial) responsibility to *educate* the public to alter these perceptions.

- ethical or value positions on other social issues should not be used as an argument to support scientific actions in the case of AIDS if such prescriptions are otherwise in conflict with the facts regarding AIDS or an independent assessment of ethical questions on AIDS. For example, homophobia or the ethical considerations of drug abuse do not constitute grounds for abrogating society's responsibility to provide care for people with AIDS or to argue that infringing on the rights of PWA/HIV+s doesn't matter because most of the people with AIDS are "second-class" citizens. Similarly, views on sex education in the schools should not be used as an argument either for or against AIDS education in the schools nor, as a further example, should advocates of "gay rights" summarily dismiss all calls for limitations on PWA/HIV+s as an unwarranted infringement of those rights.

- Having made the preceding argument, however, there may be areas in which other ethical positions may be relevant to how policy-makers respond to a problem when more than one response is possible. At a general level this may be characterized as the choice between abstention and pragmatism. In the first case, we would choose, for example, to try to eliminate intravenous drug use, to close down gay bars, to eliminate prostitution, etc. In the latter case, we would choose measures to insure clean needles (by providing free needles or disinfectants), to provide counselling/public information on safe sexual practices for homosexuals and prostitutes, to distribute condoms in bars, etc. In both cases, the policy choice and the public reaction are based on moral judgements on issues not *directly* posed by, or inherent in, AIDS.

The Right to Know

The disclosure of information about PWA/HIV + s involves a number of different constituencies:

- employers
- co-workers
- public health authorities
- family
- intimate contacts
- schools
- researchers
- non-health departments/agencies of government
- the general public

One of the first questions to be asked, before considering *who* has a right to know, is *why* there might be a right to know. Disclosure is not a victimless activity. For the individual concerned, disclosure leaves him/her subject to discrimination in the workplace, alienation at home and amongst friends, possible loss of job, loss of access to services, and general trauma and suffering. The social stigma attached to AIDS, until and unless we succeed through education in removing this stigma, makes these concerns particularly real, quite apart from all the normal arguments about the individual's right to privacy, the confidentiality of medical records, and so on. This is not to argue that these latter concerns are unimportant. Indeed, any infringement on these "normal" rights must be carefully considered lest it become a precedent for further encroachments for other reasons as well. But the special circumstances of AIDS accentuate the direct implications for the individual and therefore, make the concern all the greater. Thus, disclosure should only take place when there is a clear, definable need that will be met by disclosure.

In principle, there are two needs that *may* be served by disclosure:

- to inform those who may already have been infected in order to allow them to obtain appropriate treatment
- to prevent further infection of any other individuals

In the AIDS case, the former need would appear to be irrelevant, given the nature of the disease. The latter need, however, may be legitimate.

AIDS, as already noted, is a terminal and incurable disease. The presence of the AIDS virus in the body does not necessarily mean the person will get AIDS, although medical opinion is still divided on this question. But the essential point is that there is no known cure or effective treatment, either for AIDS itself or to eliminate the virus once an individual has the virus. Unlike other communicable diseases, including other sexually transmitted diseases, where notification of persons who may have been infected directly serves the health needs of such persons because treatment is possible, unfortunately this is not the case for AIDS. Thus, there is no public health need to be served directly for the individuals involved. One could still argue that the individual has the right to know if they might have been infected simply for the sake of knowing. But this is clearly a less compelling argument than if there was something they could do about it. And there are other complications. The individuals in question may have been intimate with more than one person, so that the source of infection may not be certain. Moreover, the uncertainties surrounding the HIV antibody test mean that it may be impossible to absolutely determine infection or the source of infection.

What we are then left with is the possibility of the virus being further spread to others. In this regard, there are two groups for whom we must be concerned:

- intimate contacts of the originally identified carrier who may not yet be infected but who could be if intimate contact continues, particularly if no preventative measures such as the use of condoms is taken.
- other persons with whom the intimate contacts of the originally identified carrier may, themselves, have intimate contact.

These groups are clearly at risk. One can argue that, in the first instance, at least one party to the relationship will know and thus preventative measures, whether in the form of abstention or the use of safe sexual practices, are likely to occur. But even if this is assured, it does not apply to the second group if the intimate contacts of the originally identified carrier are not notified.

This entire discussion, it must be recognized, rests on the question of *doubt* as to whether a positive-antibody person voluntarily will choose to tell his/her intimate contacts the test results. In other words, we are essentially concerned with state disclosure. But for state disclosure to work requires either:

- that the individual disclose the names of their intimate contacts

  or

- that the individual be investigated by the relevant authorities in order to independently determine their probably intimate contacts.

If an individual is married or has an on-going relationship with one individual, such a person can be reasonably easily identified. But beyond this, the process of trying to determine the intimate contacts of an individual almost necessarily will involve implicit if not explicit disclosure to a number of other persons, as investigators will have to talk to various known associates of the individual in their efforts to track down the subset of intimate associates. There can, moreover, be no assurance that, where a marriage or on-going relationship exists, this is the only potentially affected person.

If there is doubt as to whether an individual will voluntarily notify their contacts themselves, thus creating the justification for state disclosure, can there be any less doubt that the individual will disclose the names of all contacts to the state authorities? If the answer is no, then the state will need to independently verify the list of contacts given by the individual, effectively collapsing both methods of contact tracing into one. Therein, however, lies a possible lever for the authorities to force compliance by the individual. The individual will know that if they don't cooperate, the number of other persons who find out they are a carrier or have AIDS will be much greater. On the other hand, they have no assurance that their intimate contacts won't tell others. More importantly, this is a lever the state may not be able to use in practice insofar as the only way they can be assured the individual is cooperating is to verify this independently, in which case a promise to the individual that disclosure will be limited by cooperation has no meaning.

Looking at the disclosure issue from a slightly different angle, will disclosure provide any benefits that could not be achieved by other means? The preceding analysis suggests that the major benefit to be served by disclosure is the protection of people not yet infected who run a high risk of infection because of intimate association, once or twice removed, with a known carrier. Thus containment of the spread of the virus is the objective, given that nothing can be done for those already infected.

As an objective of public policy, containment measures cannot/should not be limited to the contacts traceable to known carriers of the virus. All other considerations aside, there simply are not enough persons who have been tested to make this an effective policy by itself. Thus, with or without such a policy, there is a need for public education and other possible measures aimed either at curbing certain types of behaviour or making them safer. But if such a policy is in place and is working effectively, do we need individual contact tracing and disclosure. It must be remembered that we are dealing with what the medical authorities have defined as an epidemic. The disease, moreover, is not confined to any one group of people defined to allow us to reach them individually. If, as a result, everyone is to be reached, what else do we accomplish by singling out certain individuals in addition? The answer, in fact, is that we may lose something because, as has been well-documented, *disclosure requirements and contact tracing lead many potential carriers to refuse testing*.

One of the related ethical issues which arises from this line of inquiry is the question of the individual's responsibility for their own actions, or, in different words, what are the limits, if any, to the state's responsibility to inform. If people in general have been advised in an appropriate way of the risks of certain kinds of behaviour and of ways to make that behaviour safer, does the state have a residual responsibility to go any further? The answer is not at all obvious.

This argument applies not only to sexual practices and drug addicts' behaviour, but also to a number of other situations. Medical workers, for example, may be considered to be at higher than normal risk of exposure if they are engaged in jobs where they are likely to be exposed to the body fluids of AIDS virus carriers, particularly blood. A medical worker, for example, might easily prick themselves or cut themselves with a needle or other sharp instrument during a blood test or surgery or some other medical procedure. But AIDS is not the only type of infection to which these workers risk exposure in such cases. More importantly, since there is no way to know who *isn't* a virus carrier, exposure is possible with any patient. The operative point is that there are so-called barrier precautions which can be taken to minimize, if not eliminate, the risk of exposure and these should be routine practice with *all* patients. If they are, then there is no obvious need to know if someone has tested seropositive for HIV antibodies. The state/employer has a clear responsibility to ensure that workers are aware of prevention practices and are provided with the necessary equipment/ environment to practise these measures. But once this is done, is there any responsibility to do more if the worker refuses to follow these practices? And if the workers do follow them, there is no need to do more or, more correctly, nothing more to be gained.

Health workers have been singled out because they are a group which is at risk because of the higher probability of contact with body fluids, in particular blood. Any job or situation of a similar nature is, however, subject to the same arguments: teachers who may have to deal with urine spills, vomit or accidents resulting in bleeding; boxers; general workplace accidents; public accidents; etc. In all these cases, preventive practices will minimize the risk and should be routine.

What all of this adds up to is a conclusion that there is no justification for disclosure to employers, co-workers, and schools and, at best, a weak justification for disclosure to family and intimate contacts. Given the expectation that many (most) infected individuals will voluntarily inform these latter two groups, the case for state disclosure virtually disappears, particularly considering the deterrent to testing which disclosure practices cause. Given these conclusions, the case for identified disclosure to public health authorities also disappears. The only remaining argument for reporting to public health authorities is for purposes of keeping track of reported cases. This need, however, will be served by anonymous or non-nominal disclosure, a practice which should pose no threat of identifying the infected individual and thus pose no threat to individual rights. Such statistics should also be available to researchers and to the general public. Any other disclosure to these groups or others (e.g. insurance companies) should take place only with the consent of the individual.

One of the additional arguments which comes in to the discussion at this point is the risks of unwarranted disclosure arising from modern information technology. Computer and communication technology have greatly increased the risk of loss of privacy and confidentiality of information. It must be recognized that the risk of unwarranted disclosure greatly increases any time information on an individual is placed in a data-bank. Without going into a detailed discussion of the need for a general policy to protect privacy and confidentiality in such cases, we can simply make the point that non-disclosure is the surest way to prevent unwarranted access to computerized information. Given that the case for mandatory reporting has not otherwise been made, this becomes an important and additional argument in the case against nominal reporting.

Quarantine / Isolation / Labelling

Most of the same arguments that have been discussed regarding disclosure also apply to the case of quarantine/isolation of PWA/HIV+s and to labelling or marking PWA/HIV+s in some visible fashion; but they apply with even greater force.

Quarantine/isolation refers to the ability of public health authorities to physically separate PWA/HIV+s from the rest of society to prevent exposure of others to the disease. Such measures are justifiable, however, only in the face of an overwhelming danger to the public safety. There is nothing in the presently known facts about AIDS to support a presumption of such a danger. When one considers that:

- casual contact cannot transmit the virus
- preventive measures to minimize risk are available

- known carriers are only a fraction of the total number of carriers
- testing to identify all carriers is both economically and administratively impossible, quite apart from the ethical considerations of mass testing
- the virus alone is necessary for AIDS to develop but *may* not be sufficient
- the potential number of AIDS virus carriers makes the economics and logistics of isolation or quarantine totally impractical if not impossible
- isolation/quarantine of known carriers may induce a sense of false security and lead to a relaxation of preventive behaviour,

the case for quarantine/isolation simply cannot be sustained on the basis of the known facts. Whether quarantine/isolation is ethical in the circumstances is irrelevant or unnecessary to ask.

Having said this, there is at least one case where some physical restraint on an individual may be justifiable in the public interest. This is the case where a carrier *knowingly* engages in transmissable behaviour without advising the other party and without taking any precautions. In this case, one can reasonably assert a purposeful endangerment of the safety of others. The question remains, however, in such a case, as to the best way to proceed against the individual. Quarantine is a discretionary action of the public health authorities. In the case outlined, it is not clear that the discretionary judgement of the health authorities constitutes due process. The case in question is, in fact, akin to a criminal act and thus, raises the question of treating it as a criminal offence.

Apart from how we feel this exception should be dealt with, it poses another problem which brings us back to the question of disclosure. Will we be able to identify individuals who knowingly transmit the disease if we do not require disclosure to the public health authorities and follow this up with contact tracing? The question this poses, in turn, is whether this argument alone is a sufficient basis to require disclosure and contact tracing, i.e., does the probability of some individuals acting in this manner constitute a sufficient threat to the public safety to infringe on the rights of all AIDS virus carriers, given the at best weak case that can be made for disclosure on other grounds? Based on present experience in jurisdictions where reporting and contact tracing are required, there is no reason to believe the threat of willful transmission is great enough to support disclosure requirements by itself.

The Workplace, Schools and Public Environments

Most of the arguments that apply to the workplace, schools and public environments have been touched upon in the discussion of disclosure and quarantine/isolation. *Unless* there is a clear, identifiable and verifiable threat to the public safety, there is no basis to support discriminatory behaviour against PWA/HIV + s.

Thus, PWA/HIV + s:

- should have the right to maintain their employment unless medically unable to do so
- should not be subject to a testing requirement to maintain their employment

- should not be subject to testing to gain employment
- should not be barred from working in the food and beverage industries
- should not be barred from working in jobs involving casual contact with the public
- should not be forced to accept work reassignment if they do not wish to do so, in cases where their positive carrier status is known
- should not be required to disclose a positive carrier status to their employers, co-workers, or others
- should enjoy access to all normal employee benefit programs including group medical and dental programs, disability and life insurance and pension plans
- should not be denied the right to attend school or university
- should not be barred from teaching positions because of carrier status
- should have all normal rights to receive medical treatment
- should not be denied access to housing

In addition, AIDS should not be used as an argument to support other forms of discriminatory behaviour. It is beyond the mandate of this report to examine such areas in detail. The point is simply that, whatever the merits of discriminatory behaviour, say, for example, on the basis of sexual preferences, the question of AIDS has no logical place in such a debate. If a school board, for example, decides not to employ a homosexual, the merits of that decision should not be influenced by the fact that homosexuals are a very high-risk AIDS group. Given that AIDS *cannot* be transmitted by casual contact, the question of whether a homosexual teacher might have AIDS is irrelevant to any other considerations in deciding whether to employ a homosexual teacher.

Assuming that there is agreement with the preceding list of PWA/HIV+s rights, an important question which still remains is how to enforce these rights when the carrier status of the individual is known. People fear AIDS and, whether out of ignorance, uncertainty, irrationality, or existing prejudices against homosexuals and drug addicts, many citizens do not want to work with or be otherwise associated with PWA/HIV+s. AIDS carries a stigma not associated with most other diseases, even sexually transmitted diseases. No one suggests, for example, that persons with a venereal disease should have to carry a card identifying themselves as such, yet a 1987 Gallop poll in the United States found 60% of respondents favoured such a requirement for AIDS or HIV+ persons. As another example, cancer or heart disease do not carry the stigma of AIDS, even though the victims' conduct or behaviour (smoking, eating habits, etc.) may be directly contributing factors.

With time and more experience in confronting the disease and those infected *and* with more public education about AIDS and preventive behaviour, public perceptions may change. But for now, they are there and must be dealt with.

When an individual is a known carrier, however that information has been disclosed, we can expect discriminatory behaviour to result. In asking how to deal with this, the type and source of the discrimination may matter. And we introduce a different dimension of individual rights – the right of persons to choose their own associates.

Consider the following scenarios:

- a doctor or dentist refuses to treat a patient who has tested positive to the virus
- parents refuse to send their children to school because a child in the school is known to be infected
- employees refuse to work in an office or factory where there is a known carrier
- the public boycotts a restaurant where an infected cook or waiter/waitress works.

In all these cases, individuals are making personal choices which can be considered their right from a certain perspective. But, it can also be argued that they must also bear the consequences of their choice. A doctor or dentist who wishes the society-granted right to practise their profession and who also chooses to discriminate without due cause should, perhaps, lose the right to practise. Parents who take their children out of school when society (government) has ruled that schooling is compulsory up to a certain age, should have to provide an alternative form of education for their children, such as a private school, at their own cost. Workers who don't want to stay in a particular work environment can resign and try to find other jobs.

But these kinds of sanctions may not work:

- the political system will be under tremendous pressure in such cases not to impose and/or enforce such sanctions
- in certain cases, there are no effective sanctions which can be applied as, for example, the restaurant scenario above; people cannot be forced to eat in a particular place, or shop, or bank, or . . .
- none of these scenarios is limited to the direct parties in its implications: in the first case, the other patients of the doctor or dentist also lose their services if sanctions are applied; in the second case, the public school system is potentially undermined; in the third case the factory or office owner loses their trained workforce with resulting loss of productivity and profits; in the fourth case, the restaurant owner may be forced out of business.

It is easy to say that sanctions against discriminatory behaviour should apply, but unfortunately the answer is not quite that easy. Nonetheless, there are precedents for such a course of action such as the civil rights actions of the 1960s or the forced busing policies of the 1970s in the United States. The political realities of the situation, however, must be recognized. Is there, then, an alternative?

One obvious answer to this question is to try to prevent the situation from arising, or, at least, minimizing the probability of it arising. This requires at least three factors:

- rigid adherence to confidentiality requirements and tight control of disclosure
- the development of codes of ethics governing the conduct of professionals in public service occupations (dentists, doctors, health services workers, teachers, etc.)
- education

These measures will help. But sanctions or penalties may also still be necessary in those cases where they are possible and questions will remain:

- can PWA/HIV+s be assured that they will receive the best or appropriate treatment from health care workers or professionals who agree to treat them only under duress?
- can one claim, where an individual is in a job involving contact with the public and the public refuses to associate with the individual or the establishment, that the individual is still capable of performing their job?
- should "innocent" victims be made to suffer because of the "sins" of others? – the problem with this argument is that it is exactly the argument used by those who would justify discrimination against PWA/HIV+s, even though the "suffering" in this case is imaginary and the notion of "sin" clearly highly subjective.

The issue becomes even more complicated when we add to the equation discrimination against *suspected* carriers versus *known* carriers. For example, it was reported in a newspaper article in October 1987 that, in April 1987, a surgeon at the Victoria General Hospital in Halifax refused to perform elective surgery on a homosexual patient until he was tested for HIV antibodies.

Finally, there is another side to the question of the rights of PWA/HIV+s to be considered and that is that it may be in their own interests, under certain circumstances, to disclose their status as a carrier or PWA. At work, for example, the individual may need to explain repeated absence due to illness or the need for a reassignment to a position less physically demanding or the need to take periodic rests during the day. Disclosure to medical personnel may be required to ensure proper diagnosis and treatment. In such cases the individual must be assured that they will not suffer a backlash from such disclosure. The only way to begin to provide such assurance is to place strict rules on individuals who are privy to such confidences and to provide strict penalties for violation of those rules. Which brings us back to the earlier arguments on limiting disclosure.

Mandatory Testing

Given all of the preceding arguments on disclosure, quarantine/isolation, labelling, and discrimination, the case for mandatory testing clearly has been disqualified.

The primary case for mandatory testing rests on the protection of society argument. As has already been shown, however, this case is not served by disclosure or quarantine/isolation or by a denial of the rights of PWA/HIV+s as citizens and workers. It then necessarily follows that mandatory testing is equally invalid.

In addition to this argument, there is a practical problem. Any logically consistent case for mandatory testing necessarily must argue for testing of everyone since potentially everyone is at risk. Mass testing, however, would be prohibitively costly. Given the uncertainties associated with the interpretation of test results, the cost is simply not justifiable, either in monetary terms or in real terms, relative to other priorities of the health care system and/or other areas of government action. Even without the uncertainties associated with the tests, mass testing would be unsupportable on these grounds. To make any sense at all, we would have to take action based on the results. What would this be? We have already argued against state disclosure in almost all cases and against quarantine/isolation or discriminatory practices. We know we can't do anything to cure infected individuals. We know, moreover, that the generalized danger to public safety is minimal or non-existent and that testing, in and of itself, does nothing to limit the spread of the virus. So what is left to be served by mass testing? The answer is nothing.

If we accept this argument on mass testing, is there still a case to be made for mandatory testing of particular groups? The answer is no – the arguments are all the same except that they apply even more strongly since testing of only some people by definition fails to identify all carriers and thus leaves open the option of infection from unidentified sources. Selective testing, moreover, could actually be counter-productive if people believe that the program is an effective protection and fail to practice proper protective measures as a result. If health workers, for example, only take precautions with known HIV-positive patients, rather than with all patients, their risk of exposure may actually be increased.

Selective populations which have been recommended by various commentators for testing are:

- homosexual or bisexual men
- drug addicts
- hospital patients
- health care workers
- government employees
- prostitutes
- prison inmates
- intimate contacts of already infected persons
- blood donors, organ donors, sperm donors
- international travellers
- immigrants

Of these only the last three represent possible exceptions to the preceding arguments.

In the case of blood donors, screening is clearly warranted in order to protect persons receiving transfusions of blood or blood products. Such persons cannot protect themselves and, moreover, have the right to assume that the blood products they are receiving are safe from all infections, including, but not limited to AIDS. The same is true for receivers of organ donations and sperm donations. But there is an important qualification to this point. Screening does not imply any necessity of disclosure, outside of the individual making the donation. The argument for screening has nothing at all to do with disclosure. The testing can and should be done through a coding system with only those people responsible for the coding being privy to the real identity of the donor.

In the case of immigrants, the argument is less straightforward. When Canada or any other country agrees to accept an immigrant, some would argue that there should be a reasonable expectation that the individual in question will make a useful contribution to the receiving country. The life expectation of a person with full-blown AIDS clearly renders this assumption invalid. This argument is less compelling for a person who tests positive to HIV antibodies but otherwise shows none of the other symptoms of ARC or AIDS. But the probability of such persons ultimately contracting the disease is high enough so as to remove a "reasonable expectation" of useful contribution. This is clearly a debatable proposition, especially considering the time span which may be involved between first exposure and death. Nevertheless, if one takes a purely parochial national view, testing of immigrants for the purpose of excluding PWA/HIV + s can be supported. Note that this argument does not rest on a case of denying PWA/HIV + s immigrant status because they are carriers of the AIDS virus, i.e., it does not rest on the public safety argument for reasons outlined previously. Nor does it rest on the argument that PWA/HIV + s will impose costs on the social and medical support system and therefore should be denied immigrant status. This could be a valid argument if, ethically, one is prepared to argue that resources should be available first to one's own citizens. Such an argument, however, is not specific to AIDS insofar as resources devoted to AIDS care can be traded off against all other areas of government activity and against all other forms of global assistance.

Mandatory testing may also be justifiable or, at least, have to be accepted in the case of insurance. Insurance underwriting is a private market activity that is based on average probabilities of risk for a certain population. AIDS or HIV-positive status clearly affects the risk factor for a particular individual and therefore it is justifiable to either deny insurance or to set higher terms in such cases.

Moreover, insofar as insurance is largely a voluntary choice for individuals, a testing requirement in order to establish eligibility or terms is not unwarranted.

Having said this, certain qualifications must be added:

1. If testing is to be required to determine insurance eligibility, it must be applied in a non-discriminatory manner. Insurance companies should not be permitted, for example, to base the requirement for a test on knowledge of an individual's lifestyle.

2. Where insurance does not normally require the disclosure of medical information, AIDS-testing should not be permitted.

3. Where insurance is provided under a group plan which does not require disclosure of specific information on members of the group, AIDS-testing should not be allowed.

4. Insurers should not have access to information on the AIDS or HIV status of an individual without the individual's expressed consent.

5. The denial of complete insurance coverage due to a positive HIV test may be questionable; a definite option would be to exclude coverage only for AIDS-related claims.

6. The case for testing and either denial or special terms applies only to new policy applicants; it is not an argument that should be allowed as a basis for cancellation or reassessment of an existing policy.

7. Any information on the HIV status of an individual which is disclosed to insurance companies must be subject to strict rules of confidentiality so as to prevent this information from falling into the hands of others.

Is there a case to be made for mandatory testing for couples getting married? There are two possible arguments in favour of this:

- to protect an unsuspecting partner from transmission of the virus
- to protect a child from contracting the virus in utero.

In the first case, one must consider that the absence of a cure makes the test of questionable value in such a situation, especially considering that, in today's more sexually permissive society, there is a high probability that the individuals will have engaged in premarital sexual relations with one another. No one who recommends a test as a condition for a marriage licence suggests that the test results should be a basis for denial of the right to marry the partner of one's choice. Rather, the use of the test would be to provide counselling and this would be of limited value in the circumstances, especially if more generalized education programming is being appropriately provided to the community. Finally, with appropriate education on AIDS, couples will be able to make their own determination of how to deal with the possibility of AIDS including a mutual decision to be tested or one partner requiring the other to be tested.

The protection of a child in utero is a legitimate concern. Again, however, the question is whether mandatory testing as a condition for a marriage licence is an effective way of dealing with this problem. First, pregnancies are not limited to married women. Second, unless one is prepared to argue that individuals testing positive should be forcibly sterilized, *an unambiguously unwarranted action*, then testing provides no guarantee that pregnancy will not still occur. The person who is most likely to question having children if they know they are infected is also likely to be able to recognize if they have engaged in high-risk behaviour and seek a test voluntarily to help to resolve their doubts.

In all of the cases where testing is at issue, the essential question is whether mandatory testing should be imposed or allowed. The weight of the arguments is that it should not be except in the cases of blood, organ and sperm donor screening, *possibly* immigration applicants, and private insurance contracts. In all of these cases, testing should be non-discriminatory and subject to strict rules of confidentiality. Otherwise, there would appear to be no compelling arguments for mandatory testing or testing without an individual's consent or knowledge: the costs would be large, and even prohibitive if mass testing was at issue, the benefits minimal at best, and the risk of unwarranted disclosure greatly increased. Insofar as most testing does little to increase the protection of society and is of no value for helping the individual, the case is not proven. With non-nominal reporting to reduce the risk of disclosure, many of the highest risk individuals will voluntarily get tested, especially with appropriate public education on AIDS; in this case, mandatory testing, is not warranted.

Other Issues

Most of the separate issues identified earlier in Section B have been dealt with in the analysis of this section. Some, however, have not. These can be grouped into three main headings:

- education and counselling
- fiscal priorities of government
- ethics and public policy decision-making.

The latter will be treated in a separate section below. For the moment, then, we conclude this section with a discussion of the first two items in this list.

Education

Repeated reference has been made already to education and counselling. Given the lack of knowledge and mis-understanding of AIDS and the imperative for infected individuals and society at large to take appropriate precautions to contain the spread of AIDS, the need for widespread education and counselling services becomes self-evident.

Having said this, however, there are important questions to be addressed concerning

- the content of AIDS education
- compulsory AIDS education in the public schools
- employer responsibilities for education
- counselling responsibilities of health care professionals
- public funding for AIDS education

The questions of public funding will be addressed in discussing the fiscal priorities of government. As for the others, the questions are as follows:

- Content – the content issue resolves essentially around the abstention vs. pragmatism debate. In other words do we seek to educate/counsel people not to engage in certain practices or to educate/counsel on how to make those practices safe. For example, should materials and media ads on drug abuse warn only of the dangers of drug abuse and counsel against taking drugs at all or should they, instead or in addition, advise those who will continue to use intravenous drugs on how to make it safer (e.g. not sharing needles)? Similar questions arise regarding homosexual sexual practices (do we seek to stamp out homosexuality or do we seek to make homosexuality safer), prostitution, adolescent sex, pre-marital sex, etc. For many people, these become moral questions. On the one side, there are those who perceive the pragmatic approach as implicitly condoning and even encouraging practices which, based on personal value systems, are considered immoral. On the other side, there are those who perceive the so-called morality of these situations as questions of individual right of choice and/or, additionally, view it as immoral not to do everything possible to decrease the spread of AIDS.

  Without directly taking sides on the moral issues involved in these cases, there is much to recommend the pragmatic approach if the dominant imperative is seen as containment of the virus. Moreover, the two approaches need not be mutually exclusive in some cases. One can, for example, advise adolescents against engaging in sexual activity at all while also advising them about safe practices. Such an approach would do much to allay concerns that the message represents the approval or condoning of such practices. In other cases, while personal value systems clearly differ on issues such as pre-marital sex or homosexual behaviour, these are activities that the government otherwise has chosen not to take moral positions on as long as they involve consenting adults acting in private. There is no obvious reason to make AIDS an exception to this position.

A further dimension of the content issue is the degree of explicitness which should be involved. This is a concern for messages/programs that are to be delivered to the general public through mass media and to programs in the school. Thus people may object to, or be offended by, TV commercials dealing with condoms or schools programs which provide descriptions of anal intercourse and so on. This issue may also come into conflict with religious beliefs and the freedom to practice one's religion free of state intrusion.

There are no easy answers to this problem. At one end it can be argued that if, to be effective, content must be explicit when required, then the pragmatic approach would limit content only by the phrase "when required". On the other end, one can argue that levels or degrees of education material/messages can be thought of, and those that are going to reach minors or the general public should be constrained in ways not necessarily required of more restricted circulation materials. This latter solution, however, has two possible problems:

- there are some people who for various reasons may not have access to, or avail themselves of, the more restricted materials. To take what may be an extreme but by no means frivolous example, illiterates may only be reachable through such mediums as mass audience television.
- minors may only have adequate access through programs in the school.

Looking at the school case by itself raises the issue of the right of parents to refuse to allow their children to take AIDS education units versus the right of children to be informed. One way to at least minimize this problem is to involve parents in briefing sessions on the content of curriculum units on AIDS and to solicit parents views on the units. Giving parents a sense that they are involved in such decisions on their children's education and simply making them aware of what is being taught may go a long way towards alleviating their fears and concerns. If after such a process, however, parents still wish their children not to take the unit, should opting out be allowed? Most jurisdictions including Nova Scotia have opted to make the delivery of an AIDS curriculum unit mandatory but to make the taking of the unit optional and to give parents the right to exercise that option on behalf of the child. This is a compromise that may be workable, particularly when combined with an effort to involve parents and to address their concerns. But it is also a position which may need to be reevaluated if the incidence of AIDS amongst adolescent school-age children begins to rise.

- Employer responsibilities can be argued in a number of ways. There is on the one hand no necessary reason to assume that employers have any greater obligation to provide AIDS education than other special groups in society. On the other hand, the workplace is an environment that will permit the public health/education authorities to reach a large number of people in a favourable setting in terms of providing a "captive" audience. Fear of AIDS in the workplace, moreover, is a very real problem and therefore there is a strong case to be made for addressing the issue in the workplace. Finally, employers should recognize that it may be in their own self-interest to provide AIDS education to their employees. Should employees face a situation of a known carrier in the workplace or even be suspicious that a co-worker or client/customer may be a carrier, an un-educated response is likely to be far more disruptive, causing an increase in absenteeism, loss of productivity, poor employee relations, etc., than an informed, educated response. Should employers then be required to offer AIDS education to employees? The arguments just cited, however valid, probably do not constitute sufficient basis for requiring employer-sponsored programs. However, a requirement to allow the relevant authorities to conduct programs in the workplace would appear to be a reasonable alternative. This then puts the question back into the realm of government fiscal priorities.

- The final question on education involves counselling responsibilities of health professionals. This issue should not, in fact, be particularly contentious. But there are some nuances which do merit discussion:

    - there is the question of health professionals who refuse association with PWA/HIV+s.
    - there is the question of special responsibilities which evolve onto the physician if the recommendations made earlier on disclosure requirements are accepted, since in this case, the physician may be the only person aware of the individual's condition and therefore the only one able to provide counselling.
    - there is the issue of special education for health professionals to allow them to fulfill the counselling role.
    - there are the special counselling needs of PWA in confronting a terminal, incurable disease.
    - counselling needs may (will) involve not only medical professionals but also social services professionals.
    - there is the pragmatic issue of allowing such counselling work to be eligible for provincial health insurance system billing, while also being mindful of the need to do this in a way which precludes disclosure of the identity of PWA/HIV+s.

If, as previously recommended, health professional associations develop a code of ethics for dealing with AIDS, consultation responsibilities should form part of such codes. Beyond this, two concerns dominate the above list:

- the need for appropriate government funding for training health professionals/social services professionals in AIDS-related counselling.
- the potential conflict between counselling needs and disclosure.

Counselling, in fact, serves two separate, albeit related, objectives:

- control of the spread of the virus
- helping the people with AIDS or HIV+ to cope with their condition.

In both cases, while the immediate attending physician can provide some counselling and, indeed, can be given training to make this role more effective, there may/will be need for specialist counselling services. But referral of the individual to such services by the attending physician may conflict with the general prohibition on disclosure. If an individual refuses such referrals on a voluntary basis, should referral be made anyway?

Given the position taken on disclosure in the above discussion of this issue, the answer must be a reluctant no. One possible way out of this problem, however, would be to set up an anonymous testing center where both specialist counselling and testing would go together and individuals would be allowed to go under assumed names or codes. Such a centre now operates successfully in San Francisco. Such a scheme, it should be noted, would require modification of the patient identification requirements of the provincial medical insurance plan.

Fiscal Priorities

As is by now obvious, containment of the virus and care for AIDS patients in a manner consistent with the preceding analysis is going to require a considerable commitment of resources by government. The question of what level of resources government is prepared to commit operates at two levels:

- at the aggregate level, AIDS-related funding must be priorized against other non-AIDS demands on government resources
- within an agreed upon allocation, the relative priority of different AIDS-related activities must be decided.

At one level, it can argued that, in a free, democratic society, ethical issues should not be given a price tag. But, unfortunately, that is not the way the world operates and, in particular, it is not the way government operates. So some global or aggregate resource constraint must be accepted as reality.

Having said this, there is little more than can be added in terms of the determination of aggregate support. All sectors of government already are subject to budgetary pressures. It is not clear that the "pie" can be made any larger at all, let alone enough larger to meet an independent assessment of the funding requirements of an "optimal" AIDS program. Thus, resources must come directly from trading-off against existing programs and policies across other sectors of government activity, including, perhaps, other health care services. In such a fiscal environment, we cannot say unambiguously that the AIDS program should get whatever resources it needs. We can say that it should get some and we can say that it is important that the policy-makers responsible for such decisions know as much as possible about the needs of an AIDS program, so as to be able to properly judge its relative priority vis-a-vis other activities. But it is the political process itself which must ultimately decide the actual level and only the political process which can decide.

The second level question, the relative priority of different AIDS-related activities, also has no easy, a priori answers. But there are some things which can be said:

- there is a responsibility to provide adequate care and levels of treatment for PWA
- there is a responsibility to carry out an education function, both in the schools and the community
- there is a responsibility to provide counselling services

- there is a responsibility to provide resources to insure that the rights of PWA/HIV + s, once determined, are protected and, equally, the rights of society, once determined

- there is a responsibility to provide appropriate testing facilities/personnel

This list could be made much longer. But, in general, these items capture most of the important areas of government responsibility we have referred to in preceding sections. Two further points, however, can be made:

- medical research support is an important item and deserves strong government support. Certainly, it could have been added to the above list. But it was purposefully not added in order to underline the point that AIDS is not just a medical problem, it is a social problem; simply providing additional funding for medical research is a "cop-out" if advocated as the only government policy response. It may be noteworthy that the initial five year, $39 million budget for the Federal Centre for AIDS approved by the federal government includes $27 million for clinical-biomedical purposes ,of which $23 million is for research and $4 million each for public education and community groups. (The federal government has since announced an increase in funding.)

- the priority of care levels/services versus education and containment of the virus is a particularly difficult question once one accepts some global resource constraint which is probably not adequate to *fully* serve either need and certainly not both. Implicit in this is a very real ethical question involving the responsibility of the PWA to accept the consequences of their own behaviour. The main problem, however, comes down to this: if we put all our resources into caring for PWA, and give little or nothing to prevention, the problem grows worse, both in terms of incidence as well as in financial terms; while if we put all our resources into prevention, the afflicted get ignored. Somehow an appropriate balance must be struck. What we must also realize, however, is that, at the present time, we have what may well be a unique opportunity to act in a way which minimizes this conflict. The care requirements for AIDS are still relatively small compared to the predictions of what they could become. Thus, not only is the conflict or resource trade-off presently less extreme than it will be in the future if we wait until the numbers get larger to act, but, by acting forcefully on the education front now, we could keep the situation from becoming as severe as the forecasts predict. In the absence of a cure, prevention is clearly the next best long-term solution. To be able to attack this problem without a relative sacrifice in care levels for those who already have the disease is indeed a unique opportunity that, if we wait, we may never see again.

One final point should be noted regarding funding priorities. Given the conclusions already reached regarding disclosure requirements, contact tracing and mandatory testing, it can additionally be noted that, if accepted, these recommendations will "free up" tremendous resources in relative terms that can be put towards care or prevention programs. Cost was not a primary factor in the conclusions we reached on these issues but, given the conclusions, the cost savings implicit in them are a strong additional consideration in coming to grips with the question of government fiscal priorities.

E. Ethics and the Public Policy Process

The public policy process, in principle, is presumed by most citizens to be ethical or, at least, it is regarded as a process which *should* be ethical. Hence, the concern (and outrage) about unethical behaviour by public officials, for example, directly follows from this presumption. But the ethics of the policy-maker or the policy-implementor are not necessarily the same as the ethics of the policy itself, quite apart from the question of whether the first is regarded as ethical in practice.

What does this mean?

As soon as we start talking about ethics and ethical behaviour, there is an immediate problem of definition. The dictionary defines ethics as,

1. a system of moral principles. 2. the rules of conduct recognized in respect to a particular class of human actions or a particular group, culture, etc. 3. moral principles, as of an individual. 4. the branch of philosophy dealing with values relating to human conduct with respect to the rightness and wrongness of certain actions and to the goodness and badness of the motives and ends of such actions. (The Random House College Dictionary, First Edition, 1980, p. 453.)

What is immediately striking about this definition is its *relativeness*. Ethics are a system of moral principles; they are rules of conduct recognized by *particular* groups or individuals; they deal with values pertaining to right and wrong actions and good and bad motives and objectives where actions can *qualify* motives and vice versa.

In the public policy sphere, this definitional ambiguity means that a series of potential contradictions can arise:

- policy-makers may act on individual issues on the basis of their own personal ethical beliefs even if those do not match the beliefs of a majority of citizens.
- policy-makers may act on individual issues on the basis of community consensus even if that is different from their own beliefs or at odds with established principles of general conduct.
- policy-makers may act on the basis of general rules of conduct even though,on an individual issue basis this creates a perception of wrong or unjust action.
- policy-makers may decide the rightness of individual actions based on the objectives to be served.
- policy-makers may decide the rightness of objectives based on the means to be employed.
- and so on.

What this list is intended to show is the range of behaviour which is possible, all of which is consistent with a definition of ethical behaviour but all of which may lead to quite different results. In other words, the principle that public policy is or should be an ethical process does not, in itself, establish an unique standard of measurement of the ethical quality of public policy.

One of the essential sources of conflict in deciding the ethics of public policy lies in the possible difference between "public" and "private" morality, the distinction itself being a moral judgement made or sanctioned by the collectivity. Thus, for example, it may be considered ethical for the state to detain or imprison an individual (albeit according to a set of well-defined rules and procedures), while it is improper for an individual to do so. Or it may be considered ethical for the state to open mail, tap telephones or "spy" on its citizens, while such action by an individual is deemed unethical.

Where there is an accepted distinction between public and private morality, the distinction usually is justified on the basis of the common good. That, however, is a principle which itself may be subject to a considerable range of interpretation, both in terms of meaning and significance. Thus, for example, the "common good" may be variously interpreted as protection of the majority, protection of individuals, protection of minority groups, etc. Or, it may be interpreted in terms of degree, with some taking the position that the protection of the collectivity is always paramount while others argue that the significance of threat or gain is what matters.

The social contract which is formed when a group of people come together to form a state or collectivity involves a voluntary surrender of certain rights or liberties by the individual on the basis that individual welfare will in fact be enhanced in the long run over the whole range of issues even though each decision will not necessarily be in each individual's own best interests. Thus, the existence of the collectivity implies necessarily

- the concept of a public good separable from the immediate good of the individual
- the principle that not all decisions will be in the interest of each member of the collectivity
- the fact that the "rightness" of certain decisions may not be evident to individuals immediately.

But these observations still do not resolve the definitional and standard of measurement problems noted above. Indeed, by explicitly introducing an equity and a time dimension to the discussion, they further add to the ambiguity rather than help to resolve it.

Two further complications may arise, both of which are present in the AIDS case:

- a lack of consensus on appropriate policy measures, in part borne of emotional response to the issue
- uncertainty regarding both the facts of the issue and its (long-run) consequences.

Consensus, it is important to note, is not necessarily synonymous with ethical. A majority of citizens may favour a government policy which, by any normal standard of community conduct, would be considered unethical. Thus, for example, the majority of Canadians supported, or at least did not question, the detainment of Japanese-Canadians during World War II. Nonetheless, a lack of consensus, i.e., the existence of strong dissensus, obviously complicates the decision-making process.

Uncertainty further fuels ambiguity because it limits the ability of the policy-maker to invoke empirical evidence to either support a given position or as a basis for deciding an issue. This is not to say that statistics should be the basis for ethical judgements but rather that, even when the ethics are clear, if the statistics aren't, the decision will be further confused.

In practice, what all of this means is that most public policy, in the words of one noted commentator on this question, simply "muddles through." (Charles Lindholm, "The Science of Muddling Through", *Public Adminstration Review*, 19, 1959, p. 79.) There is little in the public policy process as just analyzed that can provide guidance on how AIDS-related issues are to be resolved.

Having said this, there are, nonetheless, at least three principles of ethical "correctness" in public policy which can be highlighted

- individual rights can be subject to limitation in the interests of the public good
- decisions taken in the name of the public good which infringe on individual rights should be subject, however, to a test of significance, i.e., the ability to demonstrate that the gain in welfare of the collectivity outweighs the loss to the individual.
- the method chosen to achieve the decided outcomes to be sought after should, where there is a choice of methods, be that which infringes the least on individual rights.

Finally, public policy decisions must be subject to at least two tests:

- ethical consistency
- realizability.

The ethical principles underlying decisions must be consistent across decisions, and the action chosen must be one capable of being accomplished.

For the case of AIDS, the analysis of the issues and policy recommendations of this paper represent an attempt to do four things:

- to analyze the substance of the case for limitations on the rights of PWA/HIV+s in the name of the public good
- to seek methods of achieving the desired objectives of AIDS policy which involve the least limitation of anyone's rights
- to make recommendations which are consistent
- to recommend actions which can be done.

Thus we have posed the question of the significance of the threat to the public safety in terms of the threat posed by carriers of the virus. In doing so, we find that the threat is either non-existent or not significant enough to support a requirement of reportability and disclosure. If we support this position, it then necessarily follows, to be consistent, that mandatory testing also should not be required. In addition, we argued that mass testing is not able to be done and that selective testing is not consistent with established principles for protection against discrimination. Similarly, mass quarantine of carriers is not do-able nor is the significance of the possible public benefits to be realized great enough to justify such action. We have recommended education in the schools and for the general public as the most promising action to adopt to contain the spread of the disease. The threat to the public safety is not in question and containment is a priority. But containment of ***known*** carriers will not be effective both because we know only a small percentage of them and because an insistence on knowing will keep many possible carriers from being tested to find out.

The sum of our analysis adds up to an argument that we treat PWA/HIV + s according to the normal standards of treatment for citizens in general, while proceeding on a broad front to educate the public as the most promising method of containment of the spread of the virus. In other words

- given what we do know about the illness
- given what we don't know
- given the pervasiveness of the threat
- given the potential ineffectiveness of trying to contain the disease by concentrating only on *known* carriers
- given the impossibility of mass testing and mass quarantine, even assuming the benefits of such actions could be shown
- given the ignorance and misunderstanding about the disease in the minds of the public
- given the emotional basis of many people's views on AIDS (fear, homophobia, views on drug abuse, etc.),

there is no ethical basis for government to act in ways which limit the rights of PWA/HIV + s. Indeed to do so, given all of this, might well be the greatest breach of ethics of all.

At the beginning of this paper, we argued that "Individual rights . . . cannot be sacrificed without proper justification . . . ", and "It is the task of the policy-maker to . . . act on a considered, rational basis, and not succumb to the pressures borne of fear, ignorance and irrationality."

We also argued that " . . .AIDS has become a classic example of the trade-off between the rights of the individual and the rights of society. But there is a major question of whether this is a legitimate characterization. This may be the most significant moral problem of all posed by AIDS."

It is the responsibility of government to act in an ethically responsible manner. Sacrificing the rights of those who carry the virus or have the illness without proof of significant resulting benefit for the general public, and indeed a strong basis to believe that there is no such significant benefit, does not constitute such action. Government must seek a balance between society and the individual. This is fundamental to the nature of the social contract which underlies the collectivity. If we accept a limitation on the individual without significant cause or proof of benefit, we inflict a harm not only on the individual but on society as a whole because when we accept one limitation without cause, we leave the door open to many other limitations without cause. When we do that, the balance inherent in the collectivity is destroyed.

Report to the Nova Scotia Task Force on AIDS:

Public and Private Health and Care Services

Prepared by

Lynn McIntyre, M.D.

August 1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

Public and Private Health and Care Services:

Working Paper for the Nova Scotia Task Force on AIDS

The scope of this analysis of health and care services for persons with AIDS includes the following sections:

1. Care of the Adult Person with AIDS 3
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Section One:

Care of the Adult Person with AIDS

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This section reviews the total care needs of adult persons with AIDS. Hospital care, home care, social assistance and psychological support form the focus of discussion. Palliative care is dealt with in a later section.

Hospital Care for Adult Persons with AIDS (PWAs)

1. *The Victoria General Hospital (VGH)*

The Infectious Disease service at the Victoria General Hospital has become the focus of AIDS care, teaching and research in the Maritime provinces. Since February 1983, the Infectious Disease Service at the VGH has been involved in the care of 38 patients with AIDS – 30 of whom have been from Nova Scotia and 8 from other areas of the country including New Brunswick, Prince Edward Island, Ontario, and the United States.

Although the VGH operates using universal precautions, patients with AIDS are nursed on the infectious disease ward. Patients with other categories of HIV infection who require hospitalization for non-HIV-related conditions are nursed on the appropriate nursing floors and not on the infectious disease unit.

Patients with serious infections related to HIV have required prolonged and recurrent hospitalization for management of these infections and the hospital has 2-4 such patients hospitalized on a continuing basis. While hospitalized, these patients require extensive consultative care including the services of neurology, dermatology, gastroenterology, psychiatry, surgery and neurosurgery, dietetics, social service, psychology, chaplaincy, and, of course, nursing. In addition, input from family practitioners and members of high risk groups have been sought in providing the best overall care for these patients (1).

In addition to the in-patient care of these patients, the hospital operates an out-patient referral service for individuals with AIDS and less serious HIV infection. Currently an average of 10-15 patients per week are being seen in this setting. At present, approximately 100 out-patients per annum are being seen on a regular basis at varying intervals (2).

The VGH's diagnostic facilities are excellent in that there is ready access to appropriate, sophisticated immunologic studies necessary to follow these patients. In addition, there is retroviral culture capability and virus has been isolated from a number of patients. The VGH is participating in an open trial of AZT. Currently, 30 patients are receiving the drug AZT at a cost of $1,000. per patient per month (2,3,4).

2. *Hospitals Outside of Metro*

Primary care physicians and specialists in the Maritimes have frequently sought assistance in the management of AIDS cases from the VGH. The routine management of the complications of HIV infection does not require the specialized services of the VGH. However, patients with even minor complications are being referred while local internists and family practitioners become more familiar with the care of these patients. It would seem likely in future that other institutions will care for straightforward opportunistic infections such as first episode *Pneumocystis carinii* pneumonia while the VGH will continue to care for complex tertiary care problems of PWAs.

Few hospitals in Nova Scotia have had the opportunity to give medical care to PWAs. The Valley Health Services Association received its first inpatient in April 1986 and has since treated 4-6 patients (5). Patients who presented to out outpatients department prior to April 1986 were usually referred to the VGH in Halifax. All patients were treated with "Blood and Body Fluid Precautions". One hospital in Inverness also provided hospital care to an AIDS patient. The major problem with the hospitalization wasn't medical care but difficulty in maintaining patient confidentiality.

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Home Care for Persons with AIDS in Nova Scotia

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This subsection describes Nova Scotia's current home care program and identifies the home care needs of persons with AIDS and their caregivers.

Current Home Care Programs

Health, housing and social support services form the majority of the home care services in Nova Scotia. When fully implemented, the provincial coordinated home care program will provide home health and homemaker services throughout the province (1).

In-home nursing care is provided primarily by Community Health Nurses (CHNs), Certified Nursing Assistants (CNAs), and by the Victorian Order of Nurses (VON). There are

42 full-time, 4 part-time and 40 casual part-time VON nurses in 12 branches across the province, providing home nursing care in areas inhabited by about 62% of the population. The 150 CHNs and 50 CNAs in about 60 areas of the province generally do not provide home nursing in those areas served by the VON. The CHNs provide in-home psychiatric care as part of their home nursing care.

Patients are referred for home health nursing by hospital discharge planners and there are cross-referrals between VONs and CHNs. In addition to performing health care as directed by the discharging physician, the nurse liaises with the patient's physician. The nurse may (but is not required to) contact homemakers or other care providers as necessary. Some hospitals have developed their own home care services.

In terms of other health services provided in the home, there is limited Department of Health funding for home physiotherapy. These other services will become incorporated in the coordinated home care program once the core elements (homemakers, CNA's and registered nurses) are established across the province. The coordinated home care program will provide home health services without charge.

If people are to receive home care, then they clearly must be able to stay in their homes. To this end, there are several provincially financed programs. The Provincial Housing Emergency Repair Program is means-tested and provides grants to homeowners of any age needing crucial home repairs. The Small Loans Assistance Program is a means-tested, low interest loan for property upkeep or alterations. Finally, the Access-a-Home Program offers a grant for home modifications to households with at least one member confined to a wheelchair.

Homemaker Services are available through about 37 agencies in Nova Scotia. Under the coordinated home care program, homemaker agencies will be set up in areas where they do not now exist. There will also be an active attempt to coordinate the community and voluntary agencies which operate in each county and to facilitate the development of new voluntary agencies in counties which lack a full assortment of such services (1). To receive government funding, the agency must meet certain provisions, and the client must be needs-tested. Services may take the form of assistance with child care, housekeeping and meal preparation, income and expense management, and maintenance of personal hygiene and grooming. Referral is from any source, and there may or may not be fees.

Part of the Home Life Supports Program since 1984 has been extra funding for expansion of homemaker services, including home handyman, snow removal, Meals-on-Wheels, respite care, and information and referral services. However, service provision is still variable, due to waiting lists or budgetary constraints. Special funding has been provided for Demonstration Grants to volunteer or non-profit services to help people stay in their own homes. Similarly, the In-Home Supports Program has provided cost-sharing with municipalities wishing to assist families in keeping at home a relative who would otherwise require institutional placement.

Home Care for Adult Persons with AIDS

The person with AIDS may require the same home health and homemaker services that would be necessary for any disabled or chronically ill person.

Need for Home Health Services

PWAs are likely to need home health services. PWAs have a variety of health care needs depending upon the status of their general health, the type of opportunistic infection they have and whether or not they have other debilitating conditions. Home health services are not expected to take full responsibility for the care of a person who requires nursing care at home, but would complement the personal resources he/she has, such as family or volunteer support programs available to him/her.

To the present time in Nova Scotia there has been limited experience with AIDS patients in home health nursing. VON is prepared to provide some nursing assistance at home to PWAs and has done so in the past. The same would hold true for community health nurses.

The threshold for obtaining home health services has not yet been identified by the coordinated home care program nor has the range of home health services which will be offered to recipients. These are expected to be announced in September 1988. PWAs would be concerned with two thresholds: when they are "too well" to receive care and when they are "too sick" to do so.

Home care services required for PWAs fall into categories of "subacute care", "intermediate care" and "skilled nursing care". These services are provided by American home care agencies or in licensed health care settings that provide close 24-hour monitoring by a nursing staff when patients' conditions are relatively stable and not likely to require heroic interventions. Since persons with AIDS who require such care are often subject to sudden and dramatic changes in status, a high level of staff support is generally required for them (2). This type of care is expensive and labour-intensive and would probably quality the PWA as "too sick" for home care.

A more likely use of home care would relate to the patient recovering from an episode of pneumonia where the care consists largely of intermittent monitoring of improvement in health status. Gray areas of care would involve care at home for patients who are in the terminal phases of the disease and who are extremely debilitated. Effective home care under these circumstances usually requires that the patient have a viable personal support system with which the in-home nursing provider can work.

Need for Homemaker Services

PWAs are likely to need homemaker services. At intermittent points throughout the disease cycle of AIDS, normal activities such as cooking, cleaning, doing the laundry, shopping, and getting from one place to another become extremely difficult. Homemaker services may greatly assist during these times.

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Social Services in Nova Scotia Available to Persons with AIDS

This subsection was prepared by:

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The purpose of this paper is to describe Nova Scotia's current Social Services programs and to identify the specific social service needs of persons with AIDS.

Municipal and Provincial Assistance Programs

In Nova Scotia, if a person has no financial means to pay for such 'Basic Needs' as food, housing, heat, or personal needs, he/she may be 'eligible to apply' for Social Assistance benefits; these benefits are administered by Municipal and Provincial government departments.

Eligibility to be provided the above services is decided by a 'means test'. A person's assets are reviewed and if it is felt that the person cannot afford to pay for the services because of a lack of income or a lack of personal assets, he/she may be provided the services which were assessed as being required. The financial benefits which are provided by these programs are commonly referred to by recipients as 'Welfare' (Municipal) or 'Family Benefits' (Provincial).

Municipal Assistance programs are administered by local community governments. Residents of the community apply to the local government for Municipal Assistance benefits. Each municipality is able to develop its own Social Service policies, although the municipality is governed by the Social Assistance Act. Municipal Social Assistance Programs are expected to provide:

- Short term assistance for Basic needs – e.g. food, shelter costs, clothing, personal needs.
- Emergency assistance – e.g. emergency housing, food, fuel, drugs.
- Special needs – e.g. drugs, telephone, eye glasses, special diets, funeral expenses, ambulance, home support services.

The Provincial Assistance Program or Family Benefits is administered by the Province of Nova Scotia. It is a long term financial assistance program which provides financial assistance with the cost of Basic Needs (similar to Municipal Assistance). There are also long term Family Benefits programs which provide for drug coverage of the recipient (Pharmacard) and a Diabetic Assistance Program (1).

Specific Social Service Needs of Persons with AIDS

In Nova Scotia, the majority of persons with AIDS are young homosexual males. It is likely that most who become unable to work due to their illness will become dependent upon Social Assistance programs. PWAs are financially vulnerable because they have not been able to be members of the work force long enough to have accumulated any significant employment benefits, nor are they likely to have established a significant amount of personal assets. What assets they have been able to accumulate will likely be quickly depleted, leaving them dependent upon Social Assistance programs.

The person with AIDS who is not able to work due to his illness could apply for Provincial Assistance Benefits. In order to qualify, he/she would be expected to be unable to return to work for at least a year. Otherwise, the disability would be considered short-term and the person would be expected to apply for Municipal Assistance benefits.

Because the Provincial Assistance (Family Benefits) program does not provide for Special Needs or Emergency Needs, the person with AIDS who is receiving Provincial Assistance benefits would have to apply to local Municipal Assistance Services programs if Special or Emergency needs arose. In this way, a person could be dependent upon Provincial and Municipal Assistance programs at the same time.

Due to financial limitations, one community may not be able to afford to pay for programs that are available in a larger community; as well, allowances for Special Needs may not be able to be as generous. It seems that the person with AIDS could be quite vulnerable because of this situation. In general, it is expected that Municipal Social Service Departments are expected to provide financial help to clients to acquire home support services. A person with AIDS who has little or no personal support services (family, close friends, etc.) could become so ill or disabled as to require such services as a homemaker or home nursing care. The amount of service the person is able to receive would be limited by the resources which are available in the municipality in which he/she lives. A person who requires care, but cannot afford to pay for this care himself/herself may be faced with the reality of not having as much home support as he/she reasonably needs.

Persons with AIDS require a number of medications, many of which are now experimental. When these drugs are no longer considered experimental, the person with AIDS will have to purchase them him/herself if he/she does not have a drug plan. The cost of these medications could be high. As well, it is possible that some drugs would not be accepted under private drug plans for coverage due to cost. In addition, since specialized clinics are available to AIDS patients only in Halifax, transportation costs for persons with AIDS who live outside of Metro Halifzx-Dartmouth are significant.

How are persons with AIDS who are presently dependent upon assistance programs coping? Because of the limited financial income provided by these programs, persons with AIDS have had the burden of having to be very financially frugal. Because of limited funds, people have had to make changes in lifestyle, housing and, in some instances, have become more reliant upon the support and help of their family and friends. Those who have not had significant support persons available to them have been most stressed by dependence upon the Social Services system.

It has been fortunate, to this point, that most persons with AIDS have had some type of family support system (traditional and those considered non-traditional such as homosexual partners) or close friends to provide help they require. It would be reasonable to believe that, with the number of AIDS patients expected to increase, there will be more situations where families are not available.

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Psychological and Interpersonal Care and Support for Adult Persons with AIDS/HIV+

The Expert Working Group formed to develop a "model for integrated palliative care" of AIDS elicited the opinions of Canadians who care for PWAs. The respondents viewed the provision of psychological support, including help in managing feelings of loss, anger and fear, as the most important issue in palliative care for PWAs (1). For purposes of this discussion, psychological support will include areas of counselling and psychological assessment.

1. *Need for Professional Counselling and Psychological Assessment*

The family physician is often the first one to report to a person that he or she is HIV+. His most important role at this time is as counsellor. To cope with the stress of learning that one is seropositive, the patient may best be seen at frequent, two to three week intervals to discuss any concerns that the patient may have. Some patients are very hard to reach in their anger and despair over having a diagnosis of AIDS.

The physician-patient relationship should be a strong bond of support for the patient who must inform his contacts. Sensitive counseling services for these contacts must be available. The provision of such a service will naturally lead to the need for the family physician to provide adjunctive psychological treatment services—psychotherapy, family and couple therapy, and related interventions to assist patients and relatives in coping with the many ramifications of AIDS.

The psychosocial needs of AIDS patients are extensive, complex, and unique (2). PWAs have a great need to have available to them specialized counselling and support services that are beyond the purview of the family physician. Issues related to sexuality, death and dying, fear of spreading the AIDS virus, fear of isolation, fear of dying alone, loss of job, housing insurance, fear for lover's health, fear of blaming lover for illness, etc. are a few of the many issues and concerns PWAs have to face. PWAs also may need referral to appropriate agencies (legal, social, medical) to provide for their individual needs.

It is estimated that over 30 percent of the AIDS patients will develop a dementia as their primary disorder and many more will suffer impairment of cognitive and intellectual functions secondary to other aspects of the disease. The early identification and ongoing monitoring of the cognitive status of AIDS patients is crucial to their medical management and optimal adjustment. Of the multitude of psychological issues that could be addressed, psychology's initial services to the AIDS population are best utilized in the assessment of patients' cognitive functions.

Psychological and psychiatric assessment may also be required for individuals with affective disorders or suicidal ideation associated with their diagnosis.

2. *Psychological Support for Associates of PWAs/HIV +*

Health Professional Support: Few health professionals have become involved with AIDS and the emotional demands on those who have become involved are enormous. This is a devastating illness to deal with for the health care provider. Caring for young terminally ill people is very stressful. Added to this is the stress of caring for an infectious disease which the health care community as well as the public are uncomfortable with and do not appear to want to deal with. Health care providers are experiencing depression, burn-out and isolation.

Caregiver Support: Families, homosexual lovers, and close friends of the person with AIDS also need supportive counselling programs available to them (3). Caregivers need clear, accurate information on providing safe, sensitive and appropriate care to PWAs.

Caregivers face an undue amount of stress dealing on a daily basis with those affected by AIDS. There are long, increasingly frequent hospitalizations, and a generally worsening course, despite enormous effort, and many cases, great expense. The patients are typically young, well-educated people rather closely resembling the caregivers. Care providers must frequently deal with their own deeply rooted emotional reactions to homosexuality, death, or fears of contracting this deadly disease, in addition to facing the feelings and needs of the patient, and of others involved in the patient's life.

These support services can be provided through informal self-help groups, through voluntary agencies and/or through interested and trained professionals such as social workers.

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Section Two:

HIV Infection in Children: A Maritime Perspective

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Introduction

HIV infection among children in Nova Scotia poses unique social and medical problems for society. Although caused by the same virus, AIDS in children differs clinically, socially and epidemiologically from disease in adults. Many aspects of diagnosis and therapy taken for granted in adult patients do not apply to children. As an example, avoidance of the infection is not possible for children by their own actions. In addition, AIDS among children raises unique issues for society such as school and day care policies and foster care for infected children either abandoned by their parents or whose parents are unable to provide care because of their own illness.

Topics that will be addressed in this section include:

1) a summary of the current epidemiology of pediatric AIDS in Nova Scotia, Canada and North America;
2) the definition of and diagnosis of AIDS in children
3) care of the HIV infected patient in medical, educational, and social facilities;
4) therapy of pediatric AIDS; and
5) the impact of pediatric AIDS on the medical care system.

Epidemiology of Pediatric AIDS

The first report of AIDS in an adult appeared in the medical literature in May, 1981; the first pediatric case was described in November, 1982. As of September, 1987, 575 cases of AIDS in children under 15 years of age had been reported in the United States and 162 cases among 15 European countries. Twenty-six pediatric AIDS cases have been reported in Canada including two diagnosed at the Izaak Walton Killam Hospital for Children (one each from Nova Scotia and New Brunswick).

Risk factors for pediatric AIDS differ from those in adult AIDS. Whereas 85% of adult AIDS cases in Canada have been in homosexual or bisexual males, risk groups for children include frequent recipients of blood or blood products (eg, hemophiliacs) and children of a parent with or at risk for AIDS. Perinatal infection (infection that is passed from the mother to her baby around the time of delivery) is a risk for infants born to women who belong to an identifiable risk category such as injectable drug users, certain ethnic groups, and sexual partners of bisexual men. In the U.S., 78% of pediatric AIDS cases are associated with risk factors of their parents and are probably acquired at birth. Most of the remaining cases are due to transfusions. In Canada, 4 cases were transfusion-related and 22 were perinatally acquired; 19 associated with the Haitian population, one associated with a bisexual partner, one an injectable drug using partner, and in one the association was not reported.

Perinatal transmission will play an increasingly important role in pediatric HIV infection since most transfusion-related HIV infection can now be prevented. In 1985, universal screening of blood products became standard in Nova Scotia and the rest of Canada; this has markedly decreased the risk of acquiring HIV infection through transfusion. Although, it is possible for a transfused unit of blood to contain HIV and be antibody negative (if the donor had recently become infected and had not yet formed antibodies), this is not likely to be a common occurrence (estimated at less than 1:250,000 blood units) and is unlikely to contribute significantly to new HIV infections. Antigen detection tests will likely become available in the near future which will further diminish this "window" of vulnerability.

Individuals who were infected with HIV from a transfusion prior to universal screening may still develop AIDS; in children the average time after transfusion to develop AIDS is 2 years and can be as long as 6 years. Heat treatment of pooled plasma concentrates of clotting factors used in treatment of hemophilia was begun in 1984 and is effective in inactivating HIV virus. This, combined with donor screening, will virtually eliminate new cases of HIV infection through transfused clotting factors. However, a large number of hemophiliacs who have already become antibody positive may serve as a reservoir of new cases of AIDS; current data indicate that 20 - 30% of seropositive hemophiliacs have some detectable immunologic abnormalities related to HIV infection while only 2% have developed all the manifestations of AIDS.

The majority of pediatric infections now are caused by perinatal transmission. Thus as the risk of HIV infection from blood transfusion is eliminated, an increasing percentage of infections in children in the future will stem from mothers who are themselves injectable drug users or whose sexual partners either use drugs, are bisexual, or are from an endemic area. Therefore, the major focus for pediatric HIV infection must be the prevention of transmission of the virus from the infected pregnant women. Perinatal infection can occur in one of three ways: transplacentally before birth; from blood and body secretion contamination during labour and delivery; and through contaminated breast milk. Various studies have demonstrated that between 30-65% of HIV infected mothers will transmit the virus to their fetus; virtually 100% of infants thus infected will develop the disease and will die. Infected women do not need to be symptomatic to pass the infection to their infant; in fact, in 25% of cases it was the development of AIDS in the infant which led to the detection of the infection in the asymptomatic women. HIV can be transmitted during more than one pregnancy; delivery of an uninfected infant does not predict the result of subsequent pregnancies.

Diagnosis and Definition of Pediatric AIDS/HIV Infection

As experience with AIDS among children has grown, the clinical manifestations recognized and accepted as part of this disease have expanded to include those not typically found in adults. Kaposi's sarcoma and B cell lymphoma, common occurrences in adult AIDS patients, are rare in children. Hepatitis B infection, marked decrease in white blood cell numbers (peripheral lymphopenia), and an acute mononucleosis-like syndrome presentation are also uncommon among children. In contrast, high non functional antibody levels (hypergammaglobulinemia), bacterial blood infection, unusual pneumonia (lymphoid interstitial pneumonitis), and progressive neurologic disease secondary to HIV infection of the central nervous system are all common in children. In fact, failure to thrive and neurologic dysfunction play a major role in the morbidity of children with AIDS and, along with recurrent infections, constitute the major demands on the medical care system.

The unique features of AIDS in childhood were recently recognized by the Centers for Disease Control in the United States which published a revised classification system for HIV infection in children under 13 years of age (1). In addition to recognizing differences in the clinical spectrum of AIDS in children, this classification system addresses the more difficult problem of the diagnosis of HIV infection in children less than 15 months of age.

HIV infection can be diagnosed in a number of ways. Most commonly, a serum specimen is tested for evidence of HIV infection by measuring antibodies in the patient's blood by an ELISA. If a serum is repeatedly positive by ELISA, the "Western Blot" assay is done to confirm the presence of these antibodies to the HIV virus. In adults, the presence of these antibodies in one's blood is considered diagnostic proof of HIV infection. **This is not sufficient evidence in children under 15 months of age** since during pregnancy many different antibodies are normally passed from the mother to the fetus across the placenta. Women who are infected with HIV may or may not pass the virus to their infants; however, all of these mothers will pass the HIV antibody to their infants who will then test positive by the ELISA and Western Blot assays, whether or not they were actually infected. These antibodies may persist as long as 15 months.

In order to confirm HIV infection in children under 15 months of age, additional tests must be done (1). The demonstration of the virus itself (not antibody) in either blood or tissue confirms infection; this test is not widely available but must be done in an antibody positive infant if the correct diagnosis is to be made. New tests which detect the virus in serum (rather than antibody) will soon be available. Finally, demonstration of immunological abnormalities with clinical symptoms supportive of AIDS will also define a HIV infection in these antibody positive young children. HIV infection in children older than 15 months can be established by criteria similar to adults.

Care of the Patient with AIDS/HIV Infection

The Maritime experience with AIDS is limited in children; presently there are only two children with AIDS cared for in this province. Both children are alive but have complex medical problems which require continuous care and frequent hospital admissions both locally and at the Children's Hospital in Halifax.

Interviews with the parents of these two children and the more extensive experience elsewhere in North America have identified a number of concerns that must be addressed. The need for educational resource personnel and the development of community medical facilities is vital to the optimal care of the children.

Parental Concerns

1. *Lifestyle Concerns:* Both families state that caring for their child with HIV infection has meant a major change in lifestyle. Both families are involved in providing 24 hour care for their child. Neither family has any outside help. None of the parents has a social life.
2. *Parental Absenteeism from the Home:* Both families are concerned about the absence from the home of one or both parents for extended periods of time during hospitalization in Halifax. They are concerned about the effects on the other children in the family.
3. *Transportation and Other Costs:* The families must provide their own transportation to the regional or local hospitals. Both state that it is essential that they have a car and that this car is maintained and available at any time. Daily expenditure of $10 a day in gasoline is routine. One trip to the referral centre in the family car costs a minimum of $100 return a trip for one of the families. There may also be required transportation, either by air or by ambulance if the child is particularly sick, and there are concerns as to who should pay for this transportation when it is necessary.
4. *Fear of rejection if confidentiality is lost:* Both families feel that the general population in the community will reject them if their child's diagnosis were widely known.
5. *Family support groups:* Support groups to assist the household are not available in Nova Scotia.

Current Guidelines for Care of the Child with HIV Infection

A. *School:* A number of recommendations from expert bodies are available concerning school attendance of an HIV infected child. The Nova Scotia Department of Health formulated a policy in January 1986 concerning school attendance for HIV infected children (2). Similar recommendations were issued by the American Academy of Pediatrics (3), the U.S. Department of Health and Human Services (4), and the Bureau of Communicable Disease Epidemiology, Laboratory Centre for Disease Control in Ottawa (5).

B. *Hospitals:* Guidelines for hospitals in which pediatric AIDS patients are treated generally follow policies developed and published by the Centers for Disease Control in Atlanta, Georgia and the Bureau of Communicable Disease Epidemiology, Laboratory Centre for Disease Control, Ottawa, Canada. In general, these recommendations provide for placing patients with HIV infection on "blood and body fluid precautions" and do not entail any other segregation of infected patients.

C. *Day Care:* No formal guidelines are currently established for day care attendance by HIV infected children in Nova Scotia. Appropriate guidelines which take into account the epidemiology of HIV infection and the various risks involved have been published by the American Academy of Pediatrics (3) and by the Laboratory Centre for Disease Control (5).

D. *Foster Care:* No guidelines have been established in Nova Scotia for foster care of children with HIV infection. This issue has become significant in the U.S. where foster care placement has been difficult and long term residence in tertiary care facilities is common. Foster care guidelines should be established prior to problems arising. Recommendations have been published by the American Academy of Pediatrics (6), the Bureau of Communicable Disease Epidemiology, Laboratory Centre for Disease Control (5), and the U.S. Department of Health and Human Services (4).

Therapy of AIDS

Current therapy for AIDS infection in pediatric patients is limited. A number of drugs have been proposed for potential use in adults although only one drug, Azidothymidine (AZT), has been approved for therapeutic use with Canadian AIDS patients. Preliminary trials of AZT in children are now underway in both the U.S. and in Canada; the progress to introduce it for widespread use is hampered by the need to assess the drug in several age groups simultaneously. Therapeutic difficulties are not limited to the treatment of the HIV infection. AIDS patients are susceptible to a wide variety of other infections which occur because of their depressed immune system. One common type of lung infection that occurs with HIV patients, *Pneumocystis carinii*, is difficult to manage because patients do not tolerate well the drug used in its treatment (TMP/SMX).

Other areas of therapy are unique for pediatric patients. For instance, it has generally been accepted that such patients require repeated injections of intravenous gammaglobulin since their immune system is blocked by the HIV infection before it has developed. Other types of opportunistic infections which effect the gastrointestinal system and occur in pediatric patients are considerably more significant in children than in adults. Because nutrition is so crucial for children, any interruption in food intake may have disastrous consequences. Nutrition can be given by the intravenous route if it is not tolerated by the gastrointestinal system. This intravenous nutrition by "hyperalimentation" requires surgical expertise to establish the I.V. line and meticulous care for its maintenance. Children who have not developed immunity to common childhood illness such as chicken pox or measles are at severe risk for major infection if they develop these usually innocent childhood diseases. Preventive measures such as immunization with measles, mumps and rubella vaccine cannot be used since these vaccines may actually infect AIDS children producing disease. Another virus infection, CMV, can cause major problems with HIV infected children. Therapy for CMV with a new antiviral agent, Gancyclovir, is only now being evaluated. Like the other medications, this requires specific assessment for children since safety in adults can not guarantee safety in children. Thus the type of infections that occur in pediatric patients differ considerably from those in adults and therapeutic plans must be carefully evaluated.

The Medical Care System and AIDS

An area of health care not often associated with children will be increasingly in demand as pediatric AIDS cases increase. Home care services, which are just beginning in Nova Scotia, are primarily directed to the care of the elderly. Long term management of the child with AIDS will be most cost-effective if it is home based. The future utilization of the home care system by children must be anticipated. Again, the extent of utilization and a timetable cannot be predicted with the limited epidemiologic information currently available.

It is difficult to predict whether a variety of problems which have arisen in other jurisdictions will occur in Nova Scotia. The phenomenon of babies with AIDS being abandoned by their HIV infected, drug abusing parents is a reality in certain U.S. cities with the resultant placement problems assigned to various government agencies. Foster care placement has been extremely difficult in these situations, often resulting in permanent residence of these children in tertiary care children's hospitals. In these cases, expensive medical beds are utilized for custodial care purposes putting an additional burden on the acute care medical system.

In Nova Scotia, our experience is limited but indicates the high medical costs of the AIDS problem. Two children diagnosed with AIDS at the IWK Children's Hospital have spent a total of 211 days as inpatients at this hospital in the 52 patient months since diagnosis (106 days/25 months for one child, 105 days/27 months for the other). This is a rate of 49 hospital days/patient/year, close to the U.S. estimates of 30 - 40 days/year previously quoted. In addition, over 50 visits to the outpatient department have occurred, all involving multiple subspecialists and ancillary personnel. These figures do not include hospitalizations and ambulatory visits at regional and local facilities, which have also been extensive.

As treatment modalities become available, they are likely to be expensive. Routine antibiotics are often necessary and expensive. Monthly injection of intravenous gammaglobulin are also administered and cost several thousand dollars per patient per year.

Conclusion

HIV infection in children is a direct or indirect result of the behaviour of adults. Presently, 2% of AIDS cases in Canada are in children (as compared to 1.3% in the U. S.); no figures are available as to the extent of HIV infection in children. HIV infection will inevitably become a greater problem in the pediatric population as the number of infected women of child-bearing age increases. Based on the experience elsewhere, local community, medical, public health, and educational authorities must develop measures to prepare for the future care of increased numbers of HIV infected children.

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Section Three

Hospital Personnel Protection

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The scope of this section is an analysis of hospital and other health care personnel protection from HIV infection. The main study questions are:

1) What are the risks of disease acquisition in the health care setting?

2) What infection control precautions should be used in health care settings to prevent personnel from becoming infected with HIV?

3) How should exposures be handled?

4) What are the risks of patient infection if care is administered by an infected health care worker?

5) What are the requirements of a model hospital personnel protection program as it relates to HIV infection control?

Risk of Infection to Health Care Personnel

Whereas HIV or hepatitis B virus (HBV) can be detected in most body fluids of an infected person, epidemiologic evidence has implicated only blood, semen, vaginal secretions, and possibly breast milk in transmission; moreover, there is limited, if any, data to suggest that HBV or any other blood-borne pathogen is transmitted via body fluids other than those listed above (1). Although the epidemiology of AIDS is similar to that of hepatitis B, AIDS is much less contagious. The risk of a health care worker acquiring the virus in a health care setting is extremely small. In fact, nowhere in the world has a health care worker acquired AIDS from caring for someone with AIDS (2).

Seven different studies have been done on a total of 1,758 American health care workers who had parenteral exposure to blood infected with HIV virus. Although there was direct exposure to the virus, none of the workers has developed AIDS. Only 26 of the 1,758 workers tested after their exposure were seropositive. Of those 26, only three were not already in high risk groups. As no pre-screening was done on those three, it is possible that their infection was not related to their exposure at work (3). As an illustration of the difference in risk from HIV versus hepatitis B, if the same workers had been exposed in the same way to hepatitis B, 26% or 457 workers would have been infected (4).

A Canadian study recently reported on 120 health-care workers who were exposed to HIV infection. One hundred and two (85%) were females ranging in age from 20 to 60 years (median age 32 years). The 18 males ranged in age from 23 to 55 years (median age 29.5 years). Forty-six exposures were reported in 1985, 47 in 1986, and up to 1 August 1987, 27 health-care workers had been enrolled. There have been no seroconversions to date attributable to occupational exposure to HIV. One of the individuals excluded on the basis of the absence of a baseline serology result was seropositive 8 weeks post-occupational exposure. This person also had another risk factor for HIV infection (5).

Perhaps the most intense exposure to HIV for workers has occurred in hospitals like the San Francisco General where medical, nursing and lab staff have worked constantly with AIDS patients for over 5 years and unknowingly with infected people and blood for several years before that. Yet, specific studies of the staff have not shown a single HIV infection attributable to these occupational exposures (6). In fact, worldwide, there have only been about twelve individual cases of health care workers becoming infected by accidental needlesticks and splashes of infected blood on damaged skin (6,7).

According to these data, statistically the maximum risk of HIV infection following a parenteral or mucous membrane exposure to HIV-infected blood or body fluids does not exceed 3%. (8). It cannot be argued that our experience is too short to be sure about this because there have now been numerous surveillance studies in different countries all confirming the health care setting/other workplace non-epidemic. This risk can be managed adequately with the introduction of appropriate infection control precautions in the health care setting (6).

The fact that many of the reported exposures to HIV-infected blood/body fluids could have been prevented by adherence to routine infection control precautions indicates the importance of health-care worker compliance with these guidelines. The results of the US national surveillance program indicated that approximately 40% of 938 exposures were probably preventable (9).

HIV Infection Control Precautions

Infection control guidelines to prevent exposure to HIV have been reviewed periodically by expert groups to evaluate, based on current epidemiologic evidence, the appropriateness of the precautions recommended by health-care facilities.(10,11) The general consensus is that prevention of exposure to HIV can be achieved by consistent implementation of existing infection control guidelines which protect staff from occupational exposure to all bloodborne pathogens, including HIV.

Up until recently, there have been two schools of thought with regards to infection control guidelines for HIV: blood and body fluid precautions for HIV positive patients; and universal precautions whereby all patients are presumed to have HIV infection and are treated similarly. The rationale for the application of universal precautions is that selective application of blood and body fluid procedures will not eliminate occupational exposure to HIV because the infection status of hospital patients who are asymptomatic carriers of HIV is unlikely to be known. Universal precautions have now been recommended by official AIDS policy agencies in the United States and in Canada (10,11).

Revised guidelines have been published to emphasize that blood is the single most important source of HIV, HBV, and other bloodborne pathogens in the occupational setting (12). Universal precautions also apply to semen and vaginal secretions and to tissues and to most body fluids such as cerebrospinal fluid and synovial fluid. Universal precautions do not apply to feces, nasal secretions, sputum, sweat, tears, urine or vomitus unless they contain visible blood.

Protective barriers are employed in universal precautions to reduce the risk of exposure to blood, and applicable body fluids. Examples of protective barriers include gloves, gowns, masks, and protective eyewear which are selected on the basis of potential exposure.

Numerous publications have detailed the specifics of universal precautions and may be referred to for further detail (4,11-16).

Refusal to Provide Services for a Person with AIDS

At present any health care worker is protected by the Occupational Health and Safety Act which allows a worker to refuse to work where the health or safety of that worker may be jeopardized. However, it does not permit refusal to work if action were to put a patient's life or health in danger.

Because the current state of scientific knowledge suggests that AIDS cannot be transmitted through casual contact, and that the risk to health care workers is low, and that refusal to work could, in fact, jeopardize the life of a person with AIDS, health care workers cannot justifiably refuse to provide services for an AIDS patient. Such was the decision recently made by the Ontario Labour Relations Board following an inquiry involving a "refusal to work" case. It was felt that there was no danger to the nurse in treating the AIDS patient in question. Of course, this does not necessarily apply to the person with AIDS whose unusual behaviour, such as biting, could pose a threat to the nurse's safety. These "unusual" cases must be evaluated on their own merit (17).

Persons with HIV infection sometimes are also infected with cytomegalovirus, Epstein Barr virus and hepatitis B. While these viruses are possible causes of congenital infections, the risk of health care workers acquiring these infections from persons with AIDS or other patients is very small, and the risk to pregnant health care workers is no greater than for anyone else. Since there is no evidence of increased risk of infection in working with persons with AIDS, the transfer of pregnant health care workers to other work is not required (2).

The health care worker who refuses to care for an AIDS patient could justifiably be dismissed. Furthermore, the employer who allows refusal of services could also be seen as violating the Human Rights Code (4). The health care worker must therefore protect himself/herself from unnecessary risk using universal precautions guidelines.

HIV Post-Exposure Management

Protocols for management of needlestick and other exposures of health care workers have been developed. Staff at both the Victoria General and the IWK Hospital for Children are being monitored for such exposures (18,19). These individuals have remained seronegative on repeat testing.

An exposure is recorded if a health-care worker has a parenteral (eg, needlestick or cut) or mucous-membrane (eg, splash to the eye or mouth) exposure to blood or other body fluids or has a cutaneous exposure involving large amounts of blood or prolonged contact with blood – especially when the exposed skin is chapped, abraded, or afflicted with dermatitis.

The source patient should be informed of the incident and tested for serologic evidence of HIV infection after consent is obtained. Policies should be developed for testing source patients in situations in which consent cannot be obtained (eg, an unconscious patient). If the source patient cannot be identified, decisions regarding appropriate follow-up should be individualized. Serologic testing should be available to all health-care workers who are concerned that they may have been infected with HIV (1).

Basic protocols for needlestick injuries have been developed for circumstances where the source is HIV-positive, HIV-negative, of unknown HIV status, or when the source is unknown (1,11,20).

Management of the HIV-Infected Health Care Worker

While health care workers are likely to be exposed more frequently to potentially infectious body fluids, it must be recognized that a patient who has a parenteral or mucous-membrane exposure to blood or other body fluids from a health-care worker is also potentially at increased risk for HIV infection. This patient should therefore be immediately informed of the incident, and his/her exposure should be managed according to the procedures recommended for a health care worker.

The hepatitis B experience indicates that only those health-care workers who perform certain types of invasive procedures have transmitted HBV to patients. Although transmission of HIV from infected health-care workers to patients has not been reported, transmission during invasive procedures remains a possibility. Transmission of HBV from health-care workers to patients has occurred in situations (eg, oral and gynecologic surgery) in which the workers, when tested, had very high concentrations of HBV in their blood (at least 100 million infectious virus particles per ml, a concentration much higher than occurs with HIV infection), and the health-care workers sustained a puncture wound while performing invasive procedures or had exudative or weeping lesions or microlacerations that allowed virus to contaminate instruments or open wounds of patients (21).

Health-care workers with impaired immune systems resulting from HIV infection or other causes are at increased risk of acquiring or experiencing serious complications of infectious disease. Of particular concern is the risk of severe infection following exposure to patients with infectious diseases that are easily transmitted if appropriate precautions are not taken (eg, measles, varicella). Any health-care worker with an immune system disorder should be counseled about the potential risk associated with taking care of patients with a transmissible infection and should continue to follow existing recommendations for infection control to minimize risk of exposure to other infectious agents. Recommendations of the Immunization Practices Advisory Committee (ACIP) and institutional policies concerning requirements for vaccinating health-care workers with live-virus vaccines (eg., measles, rubella) should also be reconsidered for an employee for whom live-virus vaccine is contraindicated (22).

The question of whether workers infected with HIV – especially those who perform invasive procedures – can adequately and safely be allowed to perform patient-care duties or whether their assignments should be changed must be determined on an individual basis. These decisions should be made by the health-care worker's personal physician(s) in conjunction with the medical directors and personnel health service staff of the employing institution or hospital (10). Infected staff who are permitted to work with patient after this review are under no obligation to inform their patients of their serostatus. Routine screening of health care workers for HIV or hepatitis B infection is not recommended (10,20).

Model Infection Control Program for the Nova Scotia Health Care Setting

A model infection control program for the prevention of HIV trnasmission in the health care setting might include the following:

1. Initial orientation and training of all health-care workers – including students and trainees – on the epidemiology, modes of transmission, and prevention of HIV and other bloodborne infections and the need for routine use of universal blood and body fluid precautions for all patients.
2. Provision of equipment and supplies necessary to minimize the risk of infection with HIV and other bloodborne pathogens.
3. Monitoring adherence to recommended protective measures. When monitoring reveals a failure to follow recommended precautions, counseling, education, and/or re-training should be provided.
4. Provision of a counseling service, perhaps through an employee assistance program for health care workers who work with persons with AIDS.
5. Continuing health education of physicians, nurses and other hospital staff working with persons with AIDS providing regular updates on medical information, and precautions for HIV infection.

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Section Four

HIV Aspects of Dental Care

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Introduction

Rarely has one disease evoked such a strong response from patients, professionals and the general public. Dentists and their allied health care associates are no exception to this strong response and, like many, they are responding on both a professional and personal level. Professionally there has been a marked increase in attendance (500%) at continuing education programs related to AIDS while on a personal level, however, there are indications of considerable reluctance to undertake the treatment of AIDS patients in private offices. This ambivalence in not unique to dentistry but it does illustrate the concern and confusion within the profession related to this disease process.

This paper will attempt to outline major factors and their implications related to the dental treatment of patients suffering from AIDS in Nova Scotia. (1-5)

Current Situation in Nova Scotia

At the present time, there are approximately 400 dentists, 250 dental hygienists and 400 dental assistants practicing in the province, many of these in the Halifax-Dartmouth-Sackville-Bedford region. Of these 400 dentists, only a few are prepared or are involved in the treatment of known AIDS or HIV positive individuals. In two recent surveys, the primary reasons given by practitioners for their unwillingness to treat such individuals were because of concerns over (6,7):

1. spread via saliva or blood to patients, staff and family;
2. lack of proper sterilization capabilities in the dental office;
3. reaction of other patients;
4. length of incubation time;
5. transmission via aerosols;
6. honesty of infected individuals

7. fearful, ignorant staff; and

8. no known effective treatment or cure.

A number of practitioners have stated that if there were a separate, appropriately equipped facility available for them to work with AIDS patients, then they would provide these individuals with the necessary care. However, at present there are only two hospitals equipped for such comprehensive dental services: the Izaak Walton Killam Hospital for Children which provides dental care to children; and the Halifax Infirmary which provides dental care for adults. The Victoria General Hospital provides only surgical dental services to HIV-positive adults.

In late October of 1987, the Faculty of Dentistry at Dalhousie University opened a Special Care Clinic designed specifically to meet the oral health needs of hepatitis B and HIV infected patients. Dental treatment, at present, is performed voluntarily by two full-time dental faculty members who are assisted by two dental assistants. All procedures within that unit are done following the standard of care necessary for asepsis and sterilization for treating infectious patients as set forth by the American Dental Association (ADA) and the Canadian Dental Association (CDA).

Standard of Care - Current Recommendations

The first Canadian reported case of AIDS in the summer of 1981 sparked unprecedented interest in both the scientific and lay communities. The information collected about the disease to date offers dentists and the lay community both clear warnings and reassurances.(5)

Dentists and their staff are at less risk from the occupational transmission of the HIV virus than they are to other infectious diseases such as hepatitis B and herpes viruses. A total of 1,231 dentists and hygienists, many of whom practice in highly endemic areas, participated in a study to determine the prevalence of antibody to HIV. One dentist (0.1%) had HIV antibody. Although no exposure to a known HIV-infected person could be documented, epidemiologic investigation did not identify any other risk factor for infection. The infected dentist, who also had a history of sustaining needlestick injuries and trauma to his hands, did not routinely wear gloves when providing dental care (8).

Since medical history and examination cannot reliably identify all patients infected with HIV or other blood-borne pathogens, blood and body-fluid precautions should be consistently used for **all** patients. This approach is referred to as "universal blood and body-fluid precautions" or "universal precautions".(9)

Because of the nature of dental practice, dental professionals must protect themselves from exposure to infectious diseases that are transmitted via body fluids such as saliva, blood and blood products. Since it is impossible to determine all those who are at high risk or who are carriers, it is recommended that all patients be treated as potentially infectious and that dental professionals routinely employ the use of gloves, mask, and protective eyewear during all dental procedures. Despite the fact that these recommendations are endorsed by the American and Canadian Dental Associations (ADA and CDA) and the Centers for Disease Control (CDC), many dental professionals do not follow them and consequently are placing themselves and all their other patients at risk. (5,10)

Epidemiological evidence supports the fact if we follow simple barrier techniques of wearing mask, gloves and protective eyewear,the dentist's risk of contracting HIV infection is negligible. This risk is negligible because: 1) the HIV virus, although it can be isolated from saliva, is not transmitted by saliva because the inoculum via this route is insufficient to cause infection; and 2) the HIV virus is not normally acquired through needle stick injuries. Dentists should therefore be knowledgeable and follow appropriate precautions.

In addition to the use of universal precautions, it is recommended that when treating a known infectious patient there are several procedures which must be undertaken to set up and and clean up the dental operatory.

Time studies at Dalhousie within the Special Care unit have clearly demonstrated that it requires an extra 40-45 minutes prior to and at the end of each appointment to set up and clean up following the current recommended guidelines for treating an infectious patient.

At present it is stated that any infectious individual can be safely treated within the normal dental office. Freund et al. (3) and others questions this, based on the likelihood of private practitioners being able to do all that is necessary with respect to the level of asepsis required and the resultant increases in time, manpower and costs.

Oral Manifestations of HIV Virus

Dentistry has and will continue to make valuable contributions to the recognition and subsequent diagnosis of AIDS. Like a great many other diseases, individuals infected with the HIV virus may not be aware that they have acquired the infection. For many of these individuals, the dentist may be the first person to detect clinical signs indicating that the HIV infected individual has now developed AIDS or ARC. (4, 9-14)

Kaposi's sarcoma and oral candidiasis infection are the second and third most commonly found opportunistic diseases/infections seen in persons with AIDS or ARC. In addition to these two, other lesions such as oral warts, histoplasmosis, and hairy leukoplakia found on the lateral border of the tongue, found in previously healthy individuals should alert the dentist to the possibility that the individual has developed AIDS or ARC and should, therefore, be referred for further medical examination.

During the latter stages of the disease, oral care is essential to maintain the individual's ability to eat and keep potential oral infections (eg, candidiasis, periodontitis) under control. A study conducted in January 1988 indicated that Nova Scotian dentists require further information related to the manifestations and management of oral aspects of AIDS. (Cunningham et al, unpublished, 1988)

A great deal has yet to be learned about the progression from being HIV positive to the development of AIDS. Prospective studies of HIV positive individuals are needed to determine if there are any changes in the oral cavity *per se* that can be either predictive or allow an earlier intervention to prolong the health and quality of life of the infected individual.

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Section Five

Laboratory Services for HIV Infection

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Introduction

Infection with human immunodeficiency virus (HIV) is a *laboratory* diagnosis. Even when clinical symptoms become overwhelmingly suggestive of AIDS, a sophisticated microbiology laboratory continues to be required to confirm that the cause is HIV. It is therefore imperative, that provision of good quality, reliable laboratory services be high on the list of priorities for dealing with AIDS in Nova Scotia. Without such laboratory services, the acquisition of accurate data on HIV infection and AIDS in Nova Scotia is impossible. The absence of such accurate and timely laboratory data would make rational decision-making extremely difficult.

State-of-the-Art Diagnosis of HIV Infection

1. *Testing for Antibodies to HIV*

Antibodies produced by an infected individual against AIDS virus and found circulating in the blood are indicative of HIV infection. The most precise way of looking for HIV antibodies in patients suspected of having an HIV infection employs a battery of highly sophisticated laboratory tests applied in sequence and of increasing specificity. The usual first step is to utilize a very *sensitive* test [sensitivity is the ability of a test to detect individuals who are truly positive for the condition under investigation] known as Enzyme Linked Immune Sorbent Assay (ELISA), more recently known as an Enzyme Immunosorbent Assay (EIA). This test, because of its extreme sensitivity (99%) is used to screen for the presence of HIV antibody.(1) It suffers from several problems because of its sensitivity and will regularly *falsely* identify sera as positive. This is corrected by requiring all EIA positive sera to be confirmed by another test, known as a Western blot (WB), which is highly *specific* (99%) [specificity is the ability of a test to detect individuals who are truly free of the condition under investigation].(2) The testing sequence of a repeatedly reactive EIA and the Western blot is highly predictive of HIV infection, even in a population with a low prevalence of infection.(3) Laboratories using different Western blot reagents or other tests or using less stringent interpretive criteria may experience higher rates of false-positive results.

Another test which may be used as a specific confirmatory test is the Immune Fluorescent Test (IFT).(2) The IFT may be used in place of the WB test, but it is susceptible to some technical problems not encountered with the WB. The choice, evaluation and interpretation of these microbiological tests requires advanced training usually in the person of a professional microbiologist.

2. *Tests for HIV Antigens and Live Virus*

During early HIV infection, varying from three weeks to three months and very rarely longer, antibodies are not produced by the infected patient. Tests for antibody as an indication of infection will in these circumstances produce a falsely negative result.(4) The appropriate laboratory tests in these situations would be to attempt either a virus isolation or to perform an antigen capture EIA or both. These tests require special facilities and personnel and are available at the Atlantic AIDS Referral Laboratory (AARL), located at the Victoria General Hospital (VGH). The AARL is the only laboratory of its kind east of Montreal.

3. *Evaluation of Helper T-Cell (CD_4) Status in HIV Infected Patients*

Of the laboratory tests required for a diagnosis of HIV infection, one of the most important is the calculation of T_4/T_8 lymphocyte ratio in cells found in peripheral blood. It has been observed that this ratio which ordinarily is between one and two will fall below one during the disease at a time when serious secondary infective events begin to occur. It is an important test for patients considered to have progressed in disease to the AIDS stage. Measurement of these parameters is most efficiently and sensitively done on a flow cytometer, although manual methods may be employed.

4. *Tests for Prognostic Evaluation of HIV Infected Patients*

Certain tests have been found to be useful in the evaluation of a patient's status, whether they are just being passively followed or are in some active treatment protocol. A few of these tests employ clinical parameters such as the reversal of anergy [absence of the immune response to a battery of tests], weight gain, improvement in neurological abnormalities, or in opportunistic infections. Pertinent to this section are those requiring the service of a laboratory. These include the reduction in core (p24) protein or viremia, restoration of helper T (CD_4) cells, evaluation of lymphocytes for their mitogenic responses to common microbial antigens, and levels of antibodies against various viral components. These tests are now available in the Atlantic AIDS Referral Laboratory.

5. *Tests Which Serve the Multiorgan Transplant Program*

No surgeon would knowingly transplant organs or transfuse blood known to have come from an HIV infected person. The Red Cross has responsibility for assuring the security of our blood supply while the Atlantic AIDS Referral Laboratory at the Victoria General Hospital has assumed the responsibility of testing donors to be used in the Multiorgan Transplant Program.

As well as assuring that donors are not infected, it is important, because of the immunosuppressive nature of transplant procedures, that any HIV infected individuals in the recipient population be identified and possibly excluded from this additional immunological trauma.

In short, a proper HIV laboratory service to the Multiorgan Transplant Program must provide for the diagnosis of HIV infection in both the donor and recipient as well as the exclusion of any infective blood products used in the transplant procedure.

6. *Confidentiality of Laboratory Data*

A positive laboratory HIV determination, conclusively proving that an individual is infected with "the AIDS virus", has wider social and personal implications than those just related to the clinical status of the individual. Consequently the security of laboratory data is of major concern. The receipt of coded specimens minimizes the risk of a confidentiality breach.

Research Potential

In cooperation with the Federal Centre for AIDS and the Atlantic provinces, the Atlantic AIDS Retroviral Laboratory plans to undertake seroprevalence studies of anonymous population groups to assist health policy makers in identifying the extent to which the population is infected and what groups have higher prevalence rates of infection than others so that specific education and control programs can address their needs.

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Section Six

Palliative Care and Hospice Care for AIDS Patients in Nova Scotia

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The Victoria General Hospital (VGH) is the referral centre for AIDS in Nova Scotia. AIDS patients are followed by the Infectious Disease service at the Victoria General and to date the majority of AIDS patients in the province have been admitted to the Victoria General when hospitalization has been required.

AIDS is a terminal disease with an average expected life expectancy of twelve to eighteen months from the time of diagnosis. Persons with AIDS require a great deal of emotional support and most are involved with the hospital's hospice program (palliative care).

Palliative care is defined by the Palliative Care Foundation of Canada as:

> "The active, compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure or prolongation of life and when the control of symptoms – physical, emotional, and spiritual is paramount. It is a multidisciplinary approach that encompasses the patient, family, and the community."

Hospice is traditionally a service for dying people. It is important to recognize that the boundaries between palliative care and acute treatment services may become uncertain when delivered within a tertiary care setting. It is difficult to determine a time when the AIDS patient is considered terminal. His or her periods of wellness are interspersed with periods of critical life-threatening infections. No two patients have the same course.

One of the most difficult aspects of this disease is the uncertainty of day-to-day life. One never knows when the next infection will occur or how serious it will be. Some patients, unfortunately, never experience a sense of wellness and many suffer from a gradual downhill course while still others have a sudden and unremitting decline leading to death.

Hospice Care at the Victoria General Hospital recognizes that appropriate patient/family populations be defined as those who perceive themselves or their loved ones to have a life-threatening illness and needs related to the illness or the dying process that are not being met by the primary system of care.

The family of an AIDS patient must be defined and cannot be assumed to be a mother, father, wife, child, etc. A partner, lover, or close friend may be the person identified by the patient as the one he wishes to make decisions for him when the patient is unable to do so for himself. Proxy decision-making must be determined early in the course of the illness because, unfortunately, many patients develop a dementia related to the disease process and are later unable to express their wishes. At this point the wishes of the person and his partner/lover/family may be in direct conflict with each other.

Many families are unaware of the lifestyle of the son/brother at the time of diagnosis. The impact that this has on a family, coupled with a terminal disease that is generally feared and misunderstood, is immense. Often the family member has suspected the lifestyle but it has never been discussed in the open. These families experience guilt feelings, "What could they have done differently?".

Patients are encouraged to tell their families their diagnosis. The impact of this disease elicits many different reactions in families. Some families have been very supportive and are able to cope reasonably well. Often, however, the person has been living independently and the family finds it difficult to take the person home to be cared for, if it is required. The latter case is the more often seen when parents are elderly or have health problems of their own. It has been our experience that in some cases, part of a family has difficulty coping with the diagnosis. Family meetings are helpful to determine the needs of the patient and his family and who is the most appropriate one to meet these needs.

Coordination of Care

When the first AIDS patient arrived at the Victoria General, staff were ill-prepared. They did not have sufficient knowledge about the disease nor were they familiar or comfortable with homosexuality – the lifestyle of most of the affected group. Gradually over time and by actively seeking help from those in the community, staff were able to develop a sophisticated knowledge base and improved level of comfort with AIDS. This was critical to the provision of a place were the patient felt he could be cared for and felt safe.

This took time, however, but resulted in the development of an AIDS Care Team. This team meets bi-weekly and consists of ward nurses, a psychiatrist, a social worker, a hospice nurse, two pastoral care workers and a dietician.

The purpose of the team meetings are twofold: communication and support. Communication is vital, as it relates to continuity and consistency of care for the AIDS patient and family and/or significant others. Each inpatient is reviewed with those members of the team who are involved with that patient. This allows us to see if anyone is overlapping service or if something is left out. Needs for the future of the patients are discussed and solutions considered.

Education and support of team members is the second objective of the group. Different people present topics and, through discussion of concerns and questions, we offer support to each other.

During team meetings, any outpatients known to be having difficulty are discussed in an attempt to resolve these problems, and thus avoid hospital admission, if at all possible.

These rounds are also used for referral purposes. For example, if a new patient is diagnosed with AIDS and is presented at rounds and the Hospice Nurse is not involved, the patient could be referred to her if it were felt appropriate to do so.

Nurses are central to the provision of Hospice services at the Victoria General. Hospice-type care is given by a team of caregivers, consisting of three registered nurses and a group of trained volunteers. The nursing role consists of consultation, counseling, education, advocacy, clinical expertise, volunteer coordination, home support, and bereavement follow-up, as required. Volunteers have not played an active role with AIDS patients to date. One hospice nurse is assigned to a geographical area/service in the hospital and, therefore, a consistent person cares for all AIDS patients.

Needs of Health Care Workers

Caring for young terminally ill people is very stressful. Added to this is the stress of caring for an infectious disease which the health care community as well as the public are uncomfortable with and do not appear to want to deal with. In many instances, resistance is met when trying to care for these patients. Constant work is required to maintain appropriate isolation procedures. The most common reaction is to over-isolate the patient out of fear for self protection. It takes time for staff to become comfortable with isolation procedures and they must be allowed to verbalize their concern of contagion without fear of ridicule.

Many times family members of staff are concerned about their loved ones caring for AIDS patients – they worry about germs being carried home to them and their children. This may not provide a very supportive environment for staff at home.

Hospice Services

Adequate hospice services, education, and research in the community are essential if patient/families and/or significant others are to make successful transitions between the hospital and the community. Systems for networking and communication between the hospice program and existing community agencies must be strengthened to ensure the quality of hospice services.

Home care support for the patient is one of the program components of most palliative care services in Canada and yet is one of the major gaps in hospice services provision for Nova Scotians, regardless of diagnosis. In many cases, patients are kept in hospital for prolonged periods of time because there is nowhere for them to go. If they have a home, many times it is impossible for them to continue to live alone. They need more home care supports than are presently available. Twenty-four hour supervision in many cases is necessary. Nursing homes are often inappropriate since patients may require more care than is available in such facilities. The infectious nature of AIDS, linked with the possibility of confusion-dementia, may, at times, complicate placement of these patients.

Many patients return to hospital to die so that they might do so in a milieu which is caring and sensitive to their needs and at a time when they are no longer able to care for themselves at home. One of the needs we see in the future is for a free-standing hospital-affiliated hospice facility for people with AIDS. This would certainly benefit these patients by increasing their quality of life and make the best possible use of the services available.

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Section Seven:

Injection Drug Use

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Injection Drug Use and Human Immunodeficiency Virus Infection: Implications for Nova Scotia

This paper has two objectives: first, to give a brief overview of HIV infection related to injection drug use in Nova Scotia, in Canada and in other countries; secondly, to discuss implications of these findings for education, prevention and treatment in chemical dependency programs.

Injection Drug Use and HIV Infection

As of January 31, 1988, there were no Nova Scotians either seropositive for HIV or with AIDS who contracted their infection through the use of contaminated needles. Nevertheless, in various other jurisdictions, such as New York City, drug users sharing injection equipment constitute a major risk group for HIV infection. Furthermore, sexual contact with seropositive male addicts has been a significant source of HIV infections in women and, in turn, their babies.

In Canada, by January 25, 1988, there were 1,462 adult cases of AIDS. Of these, 9 were related to injection drug use alone as a risk factor, while 42 additional cases were related to injection drug use and homosexual or bisexual activity. All but one of these 51 cases were male. Thirty of the 51 cases have died.

The year of diagnosis among the nine cases where injection drug use is identified as the sole risk factor is distributed as follows: pre-1983, 2 cases; 1983 to 1985, no cases; 1986, 2 cases; 1987, 5 cases. Where both homosexual activity and injection drug use are implicated, the year of diagnosis breakdown shows a steady increase, from 1 case in 1983 to 17 in 1987, doubling every two years.

Canadian AIDS cases involving injection drug use alone as a risk factor comprise 0.9% of all cases. The combined risk factors of homosexual/bisexual activity and injection drug use add 2.9%, for a cumulative total of 3.8%. Canadian studies of HIV infection in injection drug users are relatively rare. Those available were discussed at a Federal Centre for AIDS-sponsored meeting on HIV infection and injection drug users (January 7, 1988).

Lamothe studied banked serum collected between 1985 and March 1987 in a Montreal detox facility specializing in heroin addiction. Of 152 patients, 3.9% (6) were HIV antibody positive. It is of interest to note that 40% of the 152 addicts had hepatitis B markers. Heroin primarily and cocaine secondarily were the injected drugs of abuse.

Negrete, at the same meeting, reported that Montreal General Hospital found two injection drug users of a sample of 89 (2.2%) to be HIV positive. In Vancouver, 963 injection drug users have been tested since October 1985 and 11 (1.1%) were HIV-positive. While it is reported that "shooting galleries" exist in Vancouver, Toronto and Montreal, the results available suggest that HIV-infection is in its early stages among Canadian injection drug users. The Canada Weekly Diseases Report (January 16, 1988) offers further substantiation of this point: Sekla et al (1988:5-7) found no HIV-positive cases among 203 needle users in Manitoba. Among 33 injection drug users who were also homo- or bisexual, however, 7 were HIV-infected.

In the United States, transmission through injection drug use alone accounts for 17% of all 50,583 cases to date with combined homosexual/bisexual activity and injection drug use accounting for another 8% of cases.

HIV antibody prevalence in 88 American studies of injection drug users varies considerably. While HIV antibody prevalence in New York City and Puerto Rican injection drug users ranges from 50%-65%, studies of areas other than the East Coast have shown injection drug users' HIV antibody prevalence to be under 5% (MMWR 36:801). On the other hand, Chaisson et al (1987) suggest that San Francisco's heterosexual injection drug users were, in late 1984-85, about 10% seropositive, with an emerging epidemic substantially independent of the one active among homosexual males in that city.

In Europe, injection drug abuse has become an increasingly important contributor to the AIDS epidemic, reaching American levels, at approximately 16%. Italian research pinpoints Milan as the source of the AIDS epidemic among Italian addicts: 29.5% of injection drug users' blood samples were HIV-positive (Lazzarin et al, 1987). Injection drug use is also a leading cause of HIV infection in Ireland (Dean et al, 1987). The ECP Working Group on AIDS, examining the time period 1981-84, and 11 European countries, noted that injection drug users are experiencing the most rapid spread of seropositivity. (Ebbesen et al, 1986).

In Edinburgh, Scotland, seroprevalence rose to more than 50% in a two year period (Robertson et al, 1986) with Angarano et al (1985) and Rodrigo et al (1985) documenting similar rapid increases in injection drug users' seroprevalence in Italy and Spain respectively.

Australian injection drug users studied in 1985 showed low rates of HIV infection at that time. Of 200 injection drug users sampled, only 1 homosexual male was seropositive (Blacker, P., et al, 1986).

Implications For Chemical Dependency Programs

The response to HIV-infection by Canadian addictions agencies is evolving rapidly at this time. While injection drug users in Canada do not have as high a rate of HIV-infection as those in the United States and Europe, the epidemiological evidence demonstrates how rapid transmission can be in this population. Therefore, implementation of prevention programs at primary, secondary and tertiary levels is imperative.

Primary Prevention

Two main target populations for primary prevention of HIV-infection due to injection drug use are: first, persons who do not have alcohol or other drug-related problems; secondly, people who use drugs but do not inject them.

The prevention and community education programs of the Nova Scotia Commission On Drug Dependency include a variety of community-based public education and awareness activities as well as youth and school services. These programs can and should integrate information on the risks of needle-sharing with the other information on the consequences of alcohol and other drug use. At the same time, it is important to place this information within a reasonable context, avoiding unwarranted fear arousal.

People who use drugs, but do not inject them, overlap with the "general public" referenced above to some degree, but in the event of chemical dependency, may be reached in treatment centres. In Nova Scotia, the illicit drugs most likely to be injected are cocaine and amphetamines. Persons whose drug use histories indicated exposure to these substances may be considered as being at higher risk of injection drug use; counselling of such groups should, among its other objectives, include that of preventing injection drug use and, especially, re-use of injection equipment; increased use of methadone maintenance; distribution of condoms, especially for injection drug users with multiple partners; along with counselling to reduce risk of sexual transmission.

Integration of education and counselling for HIV-risk reduction in injection drug users engaged in drug dependency treatment is a relatively straight-forward process, although it poses significant staff training and development requirements. More difficult, is access to injection drug users who do not opt for drug dependency treatment. One approach to providing the education and counselling needed by such people is to work closely with other governmental and non-governmental agencies with contact opportunities. Should there be evidence of increases in drug injection behaviour through, for example, sources in treatment agencies, police departments, or various social agencies, consideration should be given to community outreach techniques designed to engage injection drug users in counselling for risk reduction.

The various didactic components occurring within the context of drug dependency treatment should include education and counselling to prevent injection drug use. Patients who may be at risk of sexual contact with injection drug users should also be counselled on ways to reduce associated risks. As is the case with programs for the general public, the preventability of HIV-infection must be emphasized, with clear explanation of appropriate preventive measures and avoidance of excessive fear arousal.

Secondary Prevention

A number of proposals have been made to address secondary prevention concerns targetted to the population that has injected, or continues to inject, drugs but is not known to be seropositive. Among the measures proposed and, in some jurisdictions implemented, are: needle-exchange programs; distribution of instruction and supplies to clean needles and syringes; counselling for change of high-risk behaviour. Such initiatives as needle-exchange programs have been one method for initiating such contact with injection drug users not interested in treatment *per se*.

Because injection drug use in Nova Scotia does not appear to be highly prevalent at this time, the institution of such activities as needle-exchange is unwarranted. Furthermore, sterile needles and syringes are not very difficult to come by; and the rituals of needle-sharing as a part of the pleasure of getting high are less well-established here than in centres where heroin use in particular is prevalent.

One issue which will have to be addressed by treatment agencies has to do with testing current or previous injection drug users to determine whether they are HIV-positive, particularly if there are other risk factors, such as a history of homosexual, bisexual or promiscuous sexual encounters. The issues surrounding testing for HIV-infection are complex and serious.

The WHO position at this time (WHO, 1988) states that:

> "Information and education activities designed to increase awareness and bring about risk-reducing behaviour is preferable to indiscriminate HIV testing."

The document notes as well that:

> "Mandatory testing of drug injectors or their partners should not be promoted. . . [It] may. . . make what is already a covert behaviour even more difficult to identify and prevent those involved and at risk from seeking help."

Many physicians, as well as patients, feel that the economic, social and personal consequences of being found HIV-positive are so devastating that there is no reason to conduct the test unless an ARC or AIDS diagnosis needs to be confirmed. Standards proposed for HIV testing include: it be done only with the informed consent of the patient; both pre-test and post-test counselling by qualified personnel be available; test results be anonymous or, at least, more confidential than regular health information.

Tertiary Prevention

Tertiary prevention in this context refers to the treatment needs of chemically dependent persons who are HIV-positive or, for that matter, already suffer from AIDS. While this paper focusses primarily on injection drug use and HIV-infection, it is important to keep in mind that HIV-infection acquired through sexual transmission may co-exist with chemical dependency. Abrams (1987:8), for example, discusses the widespread drug and alcohol abuse in the gay male community. He notes that the human immunodeficiency virus infects those whose immune system is activated and that chemicals such as nitrate inhalants bring about such activation. Abrams concludes, with others, that:

> "It is imperative that those who have been infected with the AIDS virus withdraw from the use of any substances that can cause further damage and further loss of immune function."

For the HIV-infected individual who concurrently is dependent on chemicals, treatment benefits include the following: improved cooperation in treatment for HIV-infection, including improved likelihood that behaviours lowering the risk of infecting others will be adopted; potential that seropositive persons adopting a drug-free lifestyle will prolong the time span during which they are symptom-free; improved quality of life for AIDS sufferers.

The issues related to the treatment of chemically dependent persons suffering HIV-infection were well discussed at a forum on the subject in 1986 (NIAAA, 1987). A key point emerging from these deliberations is that an effective treatment and prevention response requires specialized training for health workers, including chemical dependency treatment staff. These training and staff development needs are outlined below.

Training and Staff Development Needs

Measures already taken in response to the emergency of HIV-infection as a health problem among drug dependent patients include the adoption of standard infection control measures within primary care facilities. An added benefit of these measures is that they further reduce the risk of staff contracting other serious health problems, currently more prevalent than HIV-infection; eg., hepatitis B.

In order to meet needs for primary and secondary prevention of HIV-infection, existing drug education materials should be reviewed, with a view to integrating information on drug-related risk factors and emphasizing the preventability of HIV-infection. Clear information on required safety measures should be available both in the community education field and in the didactic components of treatment and rehabilitation programs.

In treatment and rehabilitation, staff training for counselling skills needed with the client at risk of HIV-infection should be developed. Given that injection drug use is a less common source of HIV-infection in this jurisdiction than homosexual behaviour, and that alcohol and other drug problems among gay men are, according to various studies, relatively prevalent, it is apparent that the skills necessary for effective drug dependency counselling with gay clients should be developed further, including the ability to counsel for risk-reduction of HIV-infection through sexual contact as well as injection drug use.

Conclusion

At this time, injection drug use is not highly prevalent in Nova Scotia. A reasonable estimate of the number injecting drugs for "recreational" purposes would be about 100 persons, with very few doing so on a regular basis, and with cocaine or amphetamines rather than opiates being the main drugs of abuse. Nevertheless, both European and American data indicate that the spread of HIV-infection in a needle-sharing population can be very rapid, with devastating consequences not only for the addict, but also their sexual contacts and, in turn, potential offspring.

Therefore, measures to monitor the prevalence of injection drug use in the population treated for chemical dependency should be taken. Furthermore, education and skill development for staff in both community education and in treatment and rehabilitation should be undertaken.

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Section Eight:

The Voluntary Health Sector

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Introduction

The viewpoints put forth in this paper are those of a representative group of dedicated professionals presently working in a voluntary capacity with the Metro Area Committee on AIDS, committed to developing strategies in response to the complex social, economic, and psychological support needs (present and future) of persons with AIDS (PWA's), and persons HIV+ in this province.

Their areas of expertise cover a wide range, including family medicine, hospice, social work and pastoral care. Of significant importance is the input by persons with AIDS who are members of the PWA Support Group as well as volunteers who are actively involved in many facets of the organization.

Consolidation of Health Care System

Although this paper will focus upon the role of the Voluntary Sector in providing needed support services for those affected by AIDS, consolidation of the complete health care network is essential for the on-going, overall well-being of those utilizing these services. For the PWA and his/her family and loved ones in Nova Scotia access to private physicians, infectious disease specialists, hospital care, social service programs, psychological counselling, and dental care, as well as the support/self-help programs of MACAIDS must not be perceived by either the users or the providers as mutually exclusive services. We, as caregivers, must ensure easy access to needed services and a smooth transition each time the patient/person moves back and forth between hospital and community, or from one agency or caregiver to another. We must have mechanisms in place to bring critically important patient/person care issues into focus, to confront situation such as discrimination or refusal of service by health care providers, or refusal of access to chronic care facilities. Each branch of the total system must be interconnected; there must be communication and problem-solving on an on-going basis. This will mean that for the persons/patients, many of the commonly identified psycho-social problems will be resolved, the potential to establish control over their own lives, and to make positive choices will be maximized and their ability to experience a sense of well-being on a physical, emotional, and spiritual level will be greatly enhanced.

Correlation Between Education and Support

Education/prevention programs, while outside of the scope of this paper, are important in reducing the level of widespread panic and anxietyin the general public—a level which is in direct proportion to the alienation experienced by PWA's. The average person is oblivious to the enormous problems experiences by PWA's in their daily lives because their minds are diverted by the hysteria which continues to be fuelled in the media. Once education calms people and the stigma of AIDS is removed, the PWA will have significantly fewer stresses to deal with; as people's natural tendencies to reach out to a fellow human being in need resurface, PWA's will be able to retain their rightful place in society and their dignity and self-esteem as individuals.

Impact of Homophobia

The majority of persons with AIDS and/or antibody positive to date in Nova Scotia are homosexual or bisexual men and this trend is likely to continue, certainly in the near future. This fact accounts, in part, for the uniqueness of the public response to this disease as compared with other life-threatening illnesses such as cancer. The significance of negative views of homosexuality and hostility towards gay men must be reckoned with, both in terms of its effect on public reaction to AIDS and its effect on gay men's health in trying to cope with either the threat of AIDS or an actual diagnosis. This element of prejudice is so insidious that a heterosexual testing antibody positive or diagnosed with AIDS also deals with the fear of being labelled homosexual.

So while we can look to support models for other life-threatening illnesses and detect many similarities in terms of identified needs and programs which address these needs, developing support programs for persons affected by AIDS poses particular problems and challenges, because of the very real impact of homophobia in both well-documented and less tangible ways.

Role of Community AIDS Organizations

The role played by community AIDS organizations since the first cases were diagnosed in the US in the early 1980's is well documented. We tend to read and hear mainly about the larger organizations in metropolitan areas like New York and San Francisco, or Vancouver and Toronto. However, across Canada at this time, there are over twenty-four community AIDS groups, all under the umbrella of a national organization, the Canadian AIDS Society (CAS). These groups make a significant contribution to AIDS awareness and care through education and support programs. They also make recommendations to government regarding policies which will define our collective societal response to AIDS; the need for on-going core funding for community groups is emphasized by CAS, as well as a recognition of the limitations of the response through the voluntary sector.

What is a community health organization? Where does it fit into the health care delivery system?

A community organization grows out of a recognized need, a need which is not being met through any other source. It usually starts out quite informally with a small number of persons who are personally affected in one way or another by this need or problem. The impetus for most of the AIDS groups in Canada came from members of the community most affected, i.e., gay men; some were coping with an AIDS diagnosis; others saw friends being affected in ever-increasing numbers and wanted to do something to stop the spread of the virus, as well as to ease the tremendous physical and emotional burden faced by those with the illness. Pastoral care workers, family physicians, social workers, nurses, and family members of PWA's were also part of the initial membership of those fledgling organizations. They existed long before there were hospital protocols established regarding admission and treatment of AIDS patients, long before governments had recognized AIDS as worthy of special attention, long before any education had reached either health professionals, the schools, or the general public. Organizationally, over time, they developed more formal, complex structures to handle the ever-increasing demand for education and support programs. It became necessary to seek sources of funding to hire core staff in order to ensure that the efforts of volunteers were coordinated and that program initiatives were properly planned, implemented and evaluated. Fund-raising to supplement government funding became a necessity, as well as public relations campaigns to effectively advertise the group and its programs.

With more government involvement in AIDS education and support programs anticipated, the contributions made by voluntary AIDS organizations over the past five years require scrutiny in order to ascertain:

- What are the unique features of their approach? What is it they do best?
- What are the support needs they address?

Unique Features

- Because community groups operate at a grassroots level, they more easily gain the confidence and trust of the population they are trying most to reach. This applies to education efforts, where the difficult goal of motivating changes in sexual behaviour becomes attainable only if the persons delivering the messages are trusted. It also applies to support where it is perceived by users that the caregiver/volunteer is sensitive to their particular needs, both physical and emotional. Such volunteers are involved by choice and very often have been touched very closely by the problems of AIDS.

- They provide essential support services right in the community in a non-medical, informal setting. For persons who spend a significant portion of their time in hospitals, clinics, labs, etc., volunteer efforts bring a sense of normality, a reprieve from medical interventions.

- Because the organizations are small, there is virtually no red tape involved in accessing services. Staff tend to be "expert" because the focus of the organization is limited to AIDS. Users are reassured from their first contact that they are among caring friends.

- The possibility exists for users to become actively involved themselves in the organization. This opportunity to be of help to others in similar need is very beneficial in rebuilding the person's sense of self-worth, in making him/her feel that there is still purpose in their lives. It especially helps PWA's who survive longer and experience the death of others more recently diagnosed in their peer group to move beyond grief and guilt to positive action.

- In terms of educational efforts like workshops or guest speakers, the overall effectiveness of such events is greatly enhanced because the resource people from community AIDS organizations tend to speak from the heart. They have the ability to move their audiences because they themselves have been moved. In fact, they would find it impossible to talk about the disease AIDS without focussing on the people affected. The added dimension of eliciting a compassionate community response to AIDS is an essential part of all educational efforts.

- Being at arm's length from government, the organization can voice concerns about issues affecting the well-being of patients/persons. It can help accelerate government responses to pressing issues and can advocate on behalf of PWA's in order to prevent or challenge incidents of abuse, neglect or prejudice.

Support Needs

While the support needs of PWA's are paramount, there are a number of other individuals or groups seeking support, such as persons antibody positive and asymptomatic, persons HIV+ and symptomatic families and loved ones, caregivers and the "worried well", i.e., those in high-risk groups who deal with undue levels of anxiety and fear who have genuine support needs.

Support needs tend to fall under three main headings:

- Tangible/Practical Needs;
- Psychological/Emotional/Social Needs; and
- Self-Help/Wellness Needs.

Tangible/Practical Needs

- Financial Planning assistance (how to manage on a significantly reduced income)
- Assistance with legal matters (will, power of attorney, etc.)
- Assistance with funeral arrangements
- Assistance accessing disability pensions, social assistance, filing insurance claims
- Assistance accessing housing
- Assistance accessing homemaker services, home nursing or other home care services (i.e., resource management)
- Assistance with homemaking tasks: grocery shopping, banking, paying bills, meal preparation, house cleaning, etc.
- Assistance with transportation to appointments
- Assistance to ensure social outlets and continued contact with friends
- Assistance challenging instances of discrimination, prejudice, or breaches of confidentiality

Emotional/Psychological/Social Needs

- Pre and post test counselling to include both accurate information and coping strategies

- Help in sharing the diagnosis with families and significant others
- Help in making the emotional transitions between hospital and home, from dependence to autonomy throughout the course of the illness
- Help in dealing with changed body image and the redefining of one's sexuality
- Help for couples in coping with the added stress of diagnosis upon their relationship
- Support for families during the illness of a loved one and through the grieving period
- Assistance in asking medical questions of doctors, nurses, and other members of the health team
- On-going emotional support during times of self-doubt, guilt, depression, boredom, social withdrawal
- Assistance in maintaining social contacts and dealing with loneliness, building self-esteem
- Opportunities to talk openly with persons similarly affected
- Spiritual support; assistance in dealing with death and dying issues
- Access to professional counselling by persons sensitive to AIDS and (as appropriate) gay positive, especially during periods of crisis
- Help in coping with the dilemma of "too sick to work, too well to stay at home"
- Outlets for anger at the unfairness of one's situation, media hysteria, lack of an effective treatment plan, homophobia, lack of government response, general feeling of helplessness
- Help in maintaining a positive quality of life

Self-Help/Wellness Needs

- Access to information on the functioning of the immune system and the effect of nutrition, exercise, substance abuse, and mental attitude on levels of immunity or feelings of wellness.
- Access to accurate information on treatment options (both traditional and alternative), hospital procedures, home care options, experimental drugs and tests
- Access to information on self-help topics such as stress management, relaxation techniques including meditation, visualization, massage, self-hypnosis, and biofeedback
- Access to proper information regarding special precautions in the family setting
- The opportunity to form self-help groups, ideally with administrative and professional assistance from the community organization

- Support and motivation to maintain a sense of control over one's physical and mental health, despite the diagnosis

How Community-Based Voluntary AIDS Agencies Address Needs

Health needs for persons affected by AIDS must be dealt with in the more holistic sense of physical, psychological, social, and spiritual well-being. So, while there is no medical "cure" for AIDS (i.e., the physical level of health), healing is possible on other levels. To achieve healing despite HIV infection requires focusing attention on psychological, emotional and spiritual health. Ideally, support programs should ensure that:

1. practical needs are met with a minimum of stress for the individual;
2. a wide variety of individual and group support options are available during all the varying stages of illness and wellness characteristic of AIDS;
3. each individual ultimately is given the opportunity to choose the options which will work best for them, to participate in and remain in control of their own healing process.

A great many of the support needs listed can best be met by volunteer agencies such as MACAIDS provided that adequate funding is made available for qualified staff to (i) develop programs and (ii) to provide proper training, co-ordination, motivation and support for volunteers. The volunteer agencies play a key role in either meeting the need or making the appropriate referral.

A model voluntary, community-based AIDS agency in Nova Scotia should not be expected to meet financial needs of PWA's, but should act as an intermediary in referring the person to the appropriate social service agencies. It should play an advocacy role when a client encounters problems in dealing with government agencies; i.e., housing, application for disability, subsidized homemaking or nursing services, etc. A "Buddy System" (volunteer program which matches a trained volunteer with a PWA) is helpful in providing emotional support for PWA's at home and also to assist with such practical needs as banking, shopping, meal preparation, or transportation to appointments.

Professional counsellors must be available to voluntary AIDS organizations to provide expert and sensitive individual and group counselling. Accessing counselling through a community organization may be less threatening and concerns about confidentiality might be perceived as less of a barrier to accessing help than counselling accessed through the health care system. The volunteer agency can play a key role in counselling people regarding the HIV antibody test.

Trained volunteers can also staff AIDS helplines which provide information and permit crisis intervention counselling of individuals who wish to remain anonymous. The volunteer agency can also be the location of an AIDS resource library.

Support groups (for PWA's, persons HIV+, and others as the need arises) presently facilitated within community AIDS organizations are highly effective. It is reassuring for PWA's to have a chance to meet others experiencing the same emotions and/or physical ailments. Their sense of isolation is reduced; they learn from others in the group, and they themselves make a contribution. They are provided with a safe outlet for their feelings of anger, guilt, fear, or anxiety and have a supportive environment to express grief for fellow members who die. Thusfar, such support groups exist only in the Halifax-Metro area.

Support Initiatives of the Metro Area Committee on AIDS

The Metro Area Committee on AIDS, which until recently was the only community AIDS organization in the Atlantic Region, was formed in November, 1985 by a small group of interested persons in response to the first diagnosed cases of AIDS in the province. The impetus came from members of the gay community, who already anticipated an impending crisis. They joined forces with medical personnel, who suddenly found themselves trying to cope with widespread ignorance and fear of the disease. The committee undertook as a first priority, a workshop for health care professionals, the first of its kind in the province. Realizing the scope of the task ahead, especially in terms of education the public, they applied for and received two-year funding from the Health Promotions Branch of Health and Welfare Canada. A Program Coordinator was hired in December, 1986, and an Assistant Coordinator in May, 1987, and funding for an Education Officer was approved by the Nova Scotia Department of Health in December, 1987. The development of a volunteer Speakers Bureau in recent months is helping MACAIDS respond more effectively to its many requests for lectures and workshops.

In addition to its stated goals in terms of education, MACAIDS is committed to providing support to all persons affected by AIDS. Just a year ago, it seemed that the support needs of PWA's were being adequately met and that the main focus of our committee should be strategic planning. However, the case numbers of PWA's and persons HIV+ in the province have multiplied rapidly. It has also become apparent that persons HIV+ often experience even greater anxiety and fear than persons diagnosed and are in need of on-going support. Families, hesitant to disclose the nature of their loved one's illness to their "friends", need a place to turn for support, both throughout the illness and during the grieving period.

Of the twenty-six persons diagnosed with AIDS in Nova Scotia to date, sixteen have attended a PWA Support Group, facilitated by MACAIDS staff and assisted by Hospice at the Victoria General Hospital. Prior to January, 1987 when the first three persons came together, none of the PWA's had met each other, either in the hospital or clinic setting. There was an immense sense of relief when they initially came together and could talk openly with each other. The problem of geographic distance was solved by timing the meetings to coincide with clinic day at the Victoria General Hospital.

Eventually, several group members relocated to the Metro area, at which time the group began meeting, at their request, in the evening and outside of the hospital setting. While this group is facilitated by MACAIDS staff, we maintain communication with and receive encouragement from nursing staff at the V.G. and attending physicians at the Infectious Disease Clinic.

For persons who do not wish to participate in the group, we offer the opportunity for them to stay in contact either through individual interaction or by phone. Some already have a volunteer "Buddy", even though the program is not yet in place. Of the twenty-six cases to date, we have established contact with twenty persons as well as with PWA's moving here from other provinces.

Within the last two months, a second support group was started for persons HIV+. This group (about six persons) meets weekly and has a strong educational component since a common concern is how to stay well. The decision to participate in this group is a very difficult one, since breaches of confidentiality among members could affect employment, housing, and one' whole life drastically. For this reason, persons HIV + often seek counselling over the phone or request individual appointments.

Very few families/lovers to date have made contact seeking support. Unfortunately, in their desire to keep the diagnosis confidential, they sometimes deny themselves an outlet for their anger, frustration, and grief. This will hopefully change over time as society becomes more accepting and rational about AIDS.

Strategic planning for future support needs is the mandate of the Support Committee. They have recently produced two resource guides, one a general introduction to hospital procedures, MACAIDS programs, and community resources. The second is a legal information pamphlet for persons affected by AIDS.

The committee is presently developing the groundwork for the implementation of a Buddy System in the Metro area.

Individual counselling and facilitation of the two support groups is presently being handled by a social work counsellor, who is doing a field placement from the School of Social Work. The Board is presently looking at possible funding options for a full-time Support Coordinator.

Our volunteer component is strong and continues to grow. About thirty-five persons serve on the Board or on committees. A similar number have received orientation and training and are active as needed. Interviewing, training, and placing volunteers as well as providing continual feedback and encouragement to them is a huge task. With the present staff already over-burdened, it is becoming increasingly difficult to deal with the steady influx of persons wishing to volunteer and to coordinate the efforts of those already trained. It is the classical "Catch 22" situation – we need the volunteers, but we don't have the time to manage the Volunteer Program effectively.

In summary, MACAIDS has been responding to support needs of PWA's to the best of their ability. To nurture these programs and expand on them, there needs to be better integration with other institutions and agencies providing various types of support and assistance to PWA's, the support of PWA's outside the Metro area needs to be addressed, and long-term core funding is essential.

Section Nine:

Public Health Programming

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The scope of this section is an analysis of public health programming for HIV infection control in Nova Scotia. The main study questions are:

1) What are the essential elements of a public health HIV infection control program?

2) What is an appropriate model of public health programming for HIV infection control with respect to surveillance and contact tracing activities?

Elements of Public Health Programming for Control of HIV Infection

In the absence of a vaccine and an effective treatment, the control and prevention of HIV infection rests with efforts aimed at the reduction of HIV transmission.

Public health programming acts to control, reduce, and prevent the spread of HIV among residents with the focus being on development of a sound epidemiologic base; high-risk group and public education, HIV case follow-up; and partner counselling (1).

There is a strong tendency to talk about the AIDS problem in context of the New York, San Francisco and even Toronto experiences. Our experience in Nova Scotia has been different and caution must be exercised before programs are developed based entirely on what is happening in the United States and in more highly endemic areas of Canada. Of the elements of a comprehensive public health program directed at AIDS, surveillance of HIV infection and targeted educational efforts (particularly contact notification) emerge as key ingredients.

Surveillance of HIV Infection

Surveillance is the systematic regular ascertainment of incidence of an event or disease condition. Its main purpose is to detect changes in trends or distribution of a disease in order to initiate investigative or control measures. Surveillance of HIV infection is currently obtained through the reporting of HIV positive antibody tests and through physician reports of HIV disease.

Information on HIV infection gathered through surveillance efforts should indicate the prevalence of individuals who are seropositive as well as those who meet the case definition of AIDS. Antibody testing should be voluntary and accessible to members of high-risk groups, and should be accompanied by both pre- and post-test counseling. Confidentiality of all information gathered through surveillance efforts must be guaranteed (2,3).

Anonymity (no name linked with report) is not compatible with optimal surveillance because reporting may be duplicative and important demographic and risk factors may be omitted (4,5). Persons tested anonymously should still be offered counseling and medical evaluation, and if tested and found positive, encouraged to refer exposed contacts (1).

In addition to surveillance reports, the spread of HIV in our province may also be tracked through epidemiological investigations of the population and of subsegments of the population. Soundly collected epidemiologic data is the best source of program planning information for specific target groups.

Targeted Educational Efforts (Focus: Contact notification)

While targeted education is essential in the prevention of HIV transmission, the focus of this section will be contact notification and the provision of individual counselling.

Contact notification is the process of discreetly informing persons who may have been recently exposed, for example through sexual contact or by sharing needles, to someone who is HIV antibody positive. Through this process, these persons are provided with information which enables them to make an informed choice about seeking counseling, testing, and medical evaluation. They are also provided with information they need to reduce their risk of acquiring or spreading this virus. The goal of contact notification is to reduce the transmission of HIV by and among persons who have been exposed to HIV infected persons.

Health agencies, blood banks, and sperm and organ donor programs have been cooperating in contact identification and notification for those persons whose exposure to HIV has been through infected blood products or donated tissue. This seems to be a worthwhile use of contact notification. Contact notification for lifestyle-related infection acquisition is a more controversial area.

Contact notification has been widely used to control other infectious diseases and has been shown to be an effective intervention strategy in situations where a treatment and cure can be offered. While treatment and cure are not available with HIV infection, it has been suggested that notifying someone that they have had contact with an individual who is likely to be infected with HIV (ie., HIV antibody positive) may be an effective means of providing a health risk reduction message (1).

The efficacy of contact notification to reduce the transmission of HIV has not yet been demonstrated. However, in a low prevalence population such as Nova Scotia, contact notification is likely to remain a useful adjunct to HIV infection control (6).

Contact notification is a process involving two components:

1. identifying the at-risk person; and
2. providing some form of intervention

Contact notification must rely on the voluntary referral of high-risk contact by HIV antibody positive persons. The Department of Health has a legal right to identify information on the contacts and to ensure that contact notification occurs. Physicians also have a legal and ethical obligation to ensuring that every reasonable attempt has been made to notify contacts and prevent further spread. If the patient or the attending physician are unwilling to notify the contacts or if it cannot be assured that the contacts can be located and will seek counselling, the physician must request the assistance of the Department of Health (3).

There are several models of contact notification: client referral; physician notification; public health department notification; or some combination of the three (1,6).

With client referral, seropositive persons are encouraged to refer their contacts for counseling and testing services, and are solely responsible for that contact referral.

With physician referral, the physician of the index case assumes responsibility for notifying contacts of their exposure to HIV, and encouraging these persons to seek counseling and medical evaluation. In some cases, infected persons may be unwilling to refer their contacts personally because they anticipate some difficulty in doing so but they might trust their own physician to do so.

With public health department referral, the health agency assumes responsibility for notifying contacts of their exposure to HIV, and encouraging these persons to seek counseling and medical evaluation. In some cases, infected persons may be unwilling to refer their contacts personally because they anticipate some difficulty in doing so. Such persons use third-party referral in order to ensure that their contacts receive counseling and are offered testing.

A combination of approaches, such as contact tracing by the index individual with assistance where desired from the physician or the public health network, may be the most effective means of reaching sexual contacts. Whatever method is chosen, particular attention should be paid to locating and notifying those individuals who may otherwise be unaware that they have been exposed to HIV, specifically; women of child-bearing capacity, sex partners or persons with whom infected individuals have shared; seropositive blood donors and their sexual contacts and recipients of infected blood/blood products (6).

Some individuals who engage in high risk behaviour, including prostitution and intravenous drug abuse are hard to reach by traditional methods. Various community agencies have been reported to have acquired the skills to effectively reach these groups.(7)

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"The Pastoral Care of Persons with AIDS"
"Perfect Love Casts Out Fear"

A Paper submitted to

The Nova Scotia Task Force on AIDS

by

Rev. Robert Petite

August 1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

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Providing Pastoral Care

Some twelve years ago, while employed as an Anglican chaplain at Dalhousie University, a young Roman Catholic priest and I co-founded a group named "Sparrow" to offer support to gay christians. Since my arrival as the Rector to an inner-city Parish in downtown Halifax that ministry to gay people has intensified. During those years I have been reflecting on the christian community's understanding of human sexuality. That reflection has gone on within the context of counseling gay people who have problems reconciling their sexual orientation and their spiritual lives; and more recently over the past two years as I have sought to minister to persons living with AIDS.

Pastoral Care is the ministry of the christian community. The christian community enters into care giving with certain moral values and convictions which are extremely significant within the context of AIDS. AIDS is about sexuality, and in North America particularly about homosexuality and lifestyle as much as it is about compassion, healing and dying. It presents many prophetic challenges to the Church's traditional moral stance and understanding around human sexuality. Like Kevin Gordon, a Roman Catholic Lay theologian, my point of view is "a perspective that strives to retrieve and reappropriate in the Christian traditions no more than can credibly supported, rather than what the traditions have proclaimed." And so my theological reflection has been informed by a suspicion that there is more to be said about sexuality than has thus far been said by any of the Churches. My reflection has also been conditioned by the pastoral circumstance of ministering to gay people and persons with AIDS. Up to now the vast majority of Persons with AIDS in our community have been gay people and that will likely be the case for some time to come.

It is always important to begin with first principles and so I want to say a few words about the way in which we might consider doing pastoral care in the context of AIDS. Let's begin with a definition. Henri Nouwen, a prominent pastoral theologian speaks of care in terms of reaching out to others. "To reach out and care", he says, "we must develop an inner space, a quiet place in ourselves, where we can be hospitable and welcoming. Caring means protecting or being the custodian of another, not be enclosing him/her or locking him/her away but making a larger space for him/her". This is a wonderful definition of Pastoral Care within the context of AIDS because it not only challenges us to deal with our own personal reactions and perceptions of those who are afflicted with this disease but it also makes very clear the importance of opening up the community to the Persons with AIDS. Implicit in this definition is the necessity of overcoming built-in prejudices which prevent us from seeing the whole person. Before we can really hear and see the Person with AIDS we will need to develop that "inner quiet space" within ourselves where we are neither afraid nor threatened. We will also have to struggle with our questions around homosexuality so that we really can be welcoming and hospitable instead of keeping people at an arms distance. The notion of making a "larger space" for care is in marvellous juxtaposition with that of the "closet" in which so many gay people are forced to live. It is a wonderful experience to see a patient willing to share the nature of his/her disease and their sexual orientation with more and more people as acceptance and trust grows. Bringing one's life "into the light" is a large part of what spiritual healing is all about.

Two Models of Pastoral Care

There are at least two ways of thinking about pastoral care as it has developed in the christian tradition. The first involves a model of pastoral care in terms of order, structure and law, the emphasis being placed on the natural order fulfilled and completed by grace. People are cared for within an ordered structure of life and are encouraged to work out relationships, crises, and everyday problems in terms of established structures and norms. The sacrament of marriage is a good example of this kind of pastoral care because, while marriages may get into difficulty from time to time, people still feel they reflect the natural order of human relationships. The assumption is that if we simply allow grace and goodwill to function we will be able to work out our problems. The ground of this kind of pastoral care is that a person's life should be ordered and conform to societal expectations, that alienation can be overcome, and that problems and crises of life can be dealt with by conforming to society rather than by bringing about a change in the structures of society.

The second model of pastoral care is less concerned with order and structure and is grounded in the biblical image of God's Eschatological Rule and Promise. When life is viewed in these terms, the history of human beings is shown to be more responsive to the creative presence of the Spirit, who brings into existence what is yet to be, or what has yet to be revealed, rather than sustaining and preserving traditional structures. Pastoral care in this context might represent an interpretation of the human condition which is concerned with the development and "becoming" aspects of our lives.

There are enormous implications in the second model for human sexuality and ministry to Persons with AIDS. Both homosexual and heterosexual persons are increasingly resisting the idea that sexual lives must be confined to any one pattern. The traditional concepts of nature, the normal, and moral law are continually coming under judgment by Protestant and Catholic alike. The controversy within the Christian Community around virtually every aspect of sexuality bears witness to the fact that the traditional principles and methods of how a Christian ethic is worked out is shifting ground. This signals a difficult time for the Church, and it is by no means clear that one or the other of these models of pastoral care will provide the answers to the problems ahead. No doubt many pastoral care workers work out their relationship to those to whom they offer spiritual guidance by the use of both these models while never really consciously choosing one or the other.

The christian community must find ways to help us all develop an understanding of sexuality which reflects the purpose for which God made us sexual beings in the first place. The christian community must seek to reflect in this understanding the wisdom and insight of its own traditions, along with the discovery of contemporary knowledge in the area of human sexuality. It must seek to be in continuity with it own life as revealed in Scripture and Tradition, and at the same time bear witness to the renewing life of the Spirit in this present age: this is the tension between the two models of pastoral care which I have presented.

I find myself increasingly in the position of being an advocate for gay people in the midst of a religious tradition which not only finds the gay orientation untenable, but in large part has been the source of much of the isolation and prejudice which gay people have long experienced. It is impossible to consider providing pastoral care to Persons with AIDS and their lovers, friends and families without in some sense struggling with the whole issue of human sexuality. This fact makes the pastoral care of Persons with AIDS essentially different from the care of any other terminally ill patient. We are talking about a disease which is sexually transmitted, and this has been largely by a group of people who have thus far been ostracized by many in the christian community, and who espouse a lifestyle which many in the Church and the community have not supported. It is evident from my experience with pastoral care workers from many christian traditions that they often make their own private peace with this issue, supporting and affirming gay people, while shelving their Churches' stated theological positions on the question. Thus there is often a disfunction between what the Church says and what the Church does.

Homosexuality for the gay person is not only about genital sex but about life as a whole, informing the way in which one relates to virtually everything and everyone. The fact that this orientation can never be affirmed and celebrated but must be hidden has determined in large part what people have been able to make of it. Gay liberation and "coming out of the closet" is the refusal to accept this isolation. It is a refusal to live a life of deception and to deny one's self to oneself or to others. It is in the words of Kevin Gordon, "a sacrament of public witness of the meaning, possibilities and public face of homosexuality, the word made flesh, the incarnational witness of a human face of God, shattering the quiet and dark closet, unmasking anonymity and hypocrisy."

The following might serve as an example of the necessary connection between AIDS, homosexuality and living "in the light". At a recent forum on AIDS one pastor in the audience rose to his feet and objected to all this talk about sexual orientation. He said that he had been called to a patient's room recently by the patient himself. When the patient died he presumed that he had died of AIDS. "I don't know for sure", he said, "we never discussed it or his sexual orientation". If the patient died of cancer there would have been no reason to hide the cause of death. It would have been out in the open and both the pastor and the patient could have gotten on with the business of preparing to die, with all the necessary reconciliations which that preparation would have implied. But the fact that the person had died of AIDS, a disease which must be hidden because it implied and bore witness to his homosexuality, is of paramount importance in the way we provide pastoral care for these people. How can we hope to assist a person to grow spiritually and to prepare them for death without dealing with the many spiritual problems which this orientation and this disease has created? One wonders who the pastor really saw there in the hospital bed. Surely it was not the whole person, for I would guess that much which constituted not only his pain and grief, but his joy and fulfillment, had to remain hidden. And so the pastoral care of Persons with AIDS in our community necessarily means a ministry to gay people, and this will remain true until significant numbers in the heterosexual community come down with the disease. And even then it will still mean dealing with the stigma of being gay as assumptions are made about the sexual orientation even of these people.

It is already a great thing to attempt a great thing, and I hope the churches will at least begin to take seriously the contemporary necessity to struggle with the biblical, ethical and theological questions which the area of human sexuality demands. It is no longer sufficient to rest in easy answers which in the long run become the very justification for prejudice and violence. While, in my mind, all of the Churches are far from a satisfactory position in relation to the place of the gay person in the Christian community, pastoral care workers are called to minister in this situation. No doubt we will all bring our own particular understanding of the issues. As we enter the room of a Person with AIDS we will have numerous motivations for being there. We may care because we feel it is required in spite of the forbidden lifestyle. We may enter with a sense of moral superiority. If these are our primary motivations we will not be providing pastoral care, and we will certainly not be giving of ourselves.

These motivations and feelings are the long result of time and are difficult to overcome. I think the only way to make a beginning is in some way identifying with patient in so far as that is possible, so that we really do begin to see and feel as he or she does. We must be compassionate and learn to "suffer with" the Persons with AIDS. I have seen the parents, loved ones and friends of these people do this. They are able to accomplish this identification because their love conquers their fear and the tendency to judge.

Practical Considerations for Ministry

We have all heard stories of patients being rejected by health care workers and hospital staff because of the fear accompanying this disease. I am very glad to say that in my experience this has been rare. The pastoral care worker is not immune to the same fears which possess many other people. It is thus important to sort out in one's mind just exactly what the nature of this risk is. The medical experts have provided us with what I believe to be reasonable protocols in approaching Persons with AIDS. We simply must be comfortable with these protocols, otherwise we will be burdened with needless worry and anxiety, and distance ourselves from the sick and lonely. We need to know as well that most of our fear is grounded in our own fear of death itself. That, coupled with the fear of gay people and an inability to be comfortable with our own sexuality, are powerful combinations.

There is still much to know about this disease and its transmission. In the meantime we will have to get on with the job of caring for the sick and the dying. For the pastoral care worker that will mean having the confidence and the genuine courage to approach the Person with AIDS exorcised of our fear. Many of these will tell you of their alienation and loneliness, and of their lack of intimacy. There is a hope in the human presence, a presence which can express itself in warm and intimate ways. The simple gesture of holding someone's hand or giving them a hug has a great deal of healing power. Persons with AIDS have a particular need for this kind of presence and yet many are afraid to offer it out of fear and ignorance of the disease.

Those who work in a large hospital will be part of a team of people who will offer all kinds of assistance to the Persons with AIDS. There will be nurses, medical doctors, psychologists, psychiatrists, hospice workers, social workers, and many others. The pastoral care worker is a part of that team. It is important for him/her to realize that his/her role as a part of that team is the provision of spiritual care to Persons with AIDS. All too often pastoral care workers are tempted to adopt a clinical model within a clinical institution. The temptation is understandable, but I think it ought to be resisted. The healing message of the Christian Gospel, the work of prayer and spiritual direction, are essential to the well being of the patients. The wisdom and the skill to speak of spiritual matters and to pray with the patients when that seems appropriate are important areas of this ministry. In my experience this is what many patients expect of pastoral care workers, and what the staff expects as well.

One cannot do ministry with Persons with AIDS, see young men dying, often in great pain, isolated from many of their friends, without facing the larger questions of the meaning of human life, of suffering and of death. Whether patients come to any resolution of these questions depends upon many factors. The openness of the person to face what is happening to them, their attitude to life as a whole before they became sick, their spiritual maturity, the quality of the pastoral care worker's relationship with them, willingness to share their own personal struggle with these questions, and their ability to bear witness to the hope and promise of the Christian faith, are but a few.

Persons with AIDS who are gay are used to doing battle with God. They are often like Jacob, who will not cease to wrestle with Him until they have obtained a blessing. The demons which have taken the form of self-hate and insecurity are familiar companions, and many have exorcised them before. These demons return with a vengeance in the wake of AIDS, and this has meant that these people once again have to "gird up their loins", "brace themselves as a fighter". There are no easy answers to unjust suffering. Like Job, these men never cease to interrogate God and to seek for His justice and truth. They have found the courage to stand up to God, or at least to a certain image of Him. Yet despite the difficulty, I am awed by the many people who find their way toward resolution and meaning.

There is much which works against all of this. I cannot begin to tell you how spiritually devastating this disease has been to the gay community. It is the last straw in a long line of pestilences. They have been told for years that their love is evil and without finality, a love which leads nowhere. Sex is supposed to be all about life, body fluids are all about life, but for them they spell death. And yet the mystery of life is that in the midst of death life is reborn, and so the image of Christ is seen daily in the love and care of friends and lovers. In this they are confident that they too participate in God's love. Whether gay people will be able to speak well of God after AIDS will depend upon many things. One of the things it will certainly depend upon is the kind of support they receive from those who say they are God's friends. Perhaps in the long run Christianity will not judge AIDS, but AIDS will judge the christian community. This will be its moment of truth.

Anyone who wishes to do Pastoral Care of Persons with AIDS needs to be mindful of a few practical considerations in the day-to-day exercise of their ministry. I will list some of these that I have found in a paper written by James Gardiner, a Roman Catholic Priest doing AIDS ministry in New York City out of the context of a Parish.

1. The rites and services of the Church aren't always appropriate or even welcome. Nor are they the only things the Pastoral Care worker has to offer. We ought to meet with the person first and then schedule the rites when the person requests it, and, where possible, when family and friends and other caregivers participate.
2. Pastoral care needs to be extended beyond the Person with AIDS to family (including, perhaps especially, the lover), friends, health-care and social service professionals, and volunteers from various agencies. Serious, time-consuming follow-up has to be undertaken with the bereaved.
3. Although the AIDS diagnosis is tantamount to a death sentence, Persons with AIDS are *living* with AIDS. And some of the most extraordinary examples of heroism, loyalty, tenderness, and saintliness can be observed in the lives of these people.
4. We need to realize that the Church's lack of credibility in the gay community is an issue that continues to compromise ministry to many people with AIDS. It is an issue that needs to be acknowledged and resolved.

The Pastoral Response

Despite the limitations which this lack of credibility has created there are many things which the pastoral care worker can do. Again from Father James Gardiner:

1. Be available to persons with AIDS and their lovers, friends and families for whatever kind of ministry seems appropriate – sacramental or otherwise.
2. Learn the "language" of both the medical community and the high risk populations so that we can communicate with them without confusion on the one hand or embarrassment on the other.

3. Pray publicly and regularly for Persons with AIDS and for those who love them, those who care for them, and those who are searching for a cure.
4. Welcome the funerals of Persons with AIDS, celebrating them with dignity and care.

It is evident that as the disease spreads and more and more people are affected, models of pastoral care will not only have to be found for the hospital environment but also for the community at large. Models will have to be developed within the context of the parish ministry involving both laity and pastoral care committees, in order that the christian community may find ways to respond to the many *living* needs of the Persons with AIDS. The christian community will have to serve an advocacy role in approaching government agencies, securing housing and employment opportunities, establishing residences, community health support, counseling a a myriad of other support services. All of these constitute pastoral care in its broadest sense. It goes without saying that this will have to be done in consort with other interested individuals, community groups and agencies.

Conclusion

Persons with AIDS have come out of a great struggle, a struggle which began long before the advent of AIDS in their lives. It has been a struggle for meaning and purpose, for self-acceptance, and a struggle to work out a positive "life-style" which creates their lives anew. It is essentially a search which is not unlike that of every human being, for ultimately every kind of love and every relationship is concerned with the same thing: people searching for a meaningful, responsible and satisfying human existence.

Many Persons with AIDS have very little to do with the Church. They did have a relationship at one time, but because of what was perceived as a rejection of their very selves, they withdrew and made their own private peace with God. They withdrew largely because to stay would have been to participate in a kind of masochism. Others have remained and have carried on a constant struggles for acceptance. It is these people who have been responsible for the origin of christian gay groups such as Affirm, Dignity and Integrity. I have found a deep spirituality among many of these people. In many respects this disease has served to sanctify their lives and the lives of those around them.

When death is close at hand we all look back over our lives and see many things we would change, given the chance. It is rare a Person with AIDS who would change being gay. That is not a thing to be repented of, because in their minds and hears, it is a things which has been given, given by God himself and therefore a gift. Perhaps they feel they have not used this gift as they ought to have used it in all circumstances. This can be said of all of the gifts God has given to each and everyone of us. But despite painful struggle, rejection and now this terrible disease, they are almost all still willing to rejoice, to laugh and to live without bitterness. In the midst of all this tragedy this is the miracle which continues to astound and encourage me. It is the sign of true healing.

I have found little to pity in these lives, and much to admire. In the words of Camus, "There are more things in men to admire than to despise", and that there is a "never ending fight against terror and its relentless onslaughts . . . by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers". Perhaps it is this attitude of acceptance and affirmation which will enable everyone to approach the Person with

AIDS with a deep sense of humility, and which will help all of us eventually to see the healing they bring, too, to our lives, by the example they give in the struggle with this awful disease.

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Teaching Children Hygienic Procedures
To Reduce The Risk Of Infection

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The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

Executive Summary

In response to the AIDS epidemic there has been an increasing awareness of the need to educate the general public about procedures and health practices that can reduce the risk of infection to the HIV virus and to other blood-borne diseases. While more specific precautions may apply depending on the setting and the circumstances, one universal precaution is the need to immediately and thoroughly wash hands and other skin surfaces that are contaminated with blood or body fluids containing visible blood.

An important question arises as to what age should instruction begin that would help children understand the need to avoid exposure to blood and body fluids and upon exposure, to implement disinfection procedures.

This paper discusses the issues involved in answering this question. A distinction is made between teaching children the hygienic procedures and when to perform them as opposed to providing children with the information that would enable them to develop a higher awareness of why those hygienic procedures are important. For example, parents routinely teach their children at a young age to wash their hands after using the toilet. Children first learn this action by rote without understanding the broader concepts of infection control. Only later do they gain the necessary cognitive maturity to achieve true understanding of the issues involved.

Thus, the paper recommends that parents could begin teaching children when they are between three to fours years of age the universal precaution of immediately washing skin surfaces exposed to blood and to avoid touching the blood or body fluids containing blood of others.

The paper further recommends that by the age of five to seven years children have reached a level of cognitive development that would allow them to begin developing an understanding of why the hand washing behaviour is important and necessary. Specific teaching strategies and techniques for these two developmental stages are outlined.

Introduction

The AIDS epidemic has forced an examination of many aspects of everyday living—from intimate sexual practices to governmental policies of human rights. Major attention has been given to understanding the biological nature of the HIV virus and to reducing the spread of the HIV virus in the general population. Central to the effort of reducing the spread of the virus has been an unprecedented public education program. The program to date has had the difficult task of trying to allay the public's often unrealistic fear of contagion while at the same time providing information on personal practices that could reduce the individual's risk of infection.

The fact that the AIDS epidemic has touched every age group, including young children, has meant that questions about the optimal way to educate the general public about the HIV virus have had to be placed in a developmental framework. For example, there has been recent debate about the age at which it is appropriate to begin education about sexuality and the precautions that might be taken in sexual practices to reduce the risk of infection from the HIV virus.

While this broad issue of sex education has dominated the headlines, there is a related issue concerning the instruction of basic hygiene and its role in reducing the risk of infection. The importance of simple, careful hand washing in reducing the risk of infection has been known for decades. Immediate and thorough washing of hands and other skin surfaces that have been contaminated with blood and/or body fluids containing visible blood is recommended as a way of reducing the risk of transmission of the HIV virus and other blood-borne pathogens.

In response to this recommendation several recent papers (Black, 1986; Bower, 1986; Council for Exceptional Children, 1986; Iowa State Department of Educuation, 1986; McCormick, 1986) have discussed the need to have policies within school to encourage safe hygienic practices by both staff and pupils. There has been little concrete discussion in the literature, however, as to the specifics of what such a program might entail, particularly a program framed in light of the AIDS epidemic and the specific need to wash hands after exposure to blood.

This paper discusses the issues that are involved in considering a program designed to increase safe hygienic practices by children. Although previous considerations of this topic in the literature have been limited to discussions of programs for school age children, this paper presents the position that strong consideration should be given to starting the instructional process in the home prior to enrolment in school and prior to classroom education programs. This would obviously entail a public education program that would be geared to convincing parents of the importance of teaching safe hygienic practices to their children and would provide them with simple guidelines about how to do it.

The development of rule governed behaviour

The question of how children learn social rules has been the subject of much investigation by psychologists, particularly since the early 1930's when Jean Piaget published his seminal work, *The Moral Judgement of the Child*. According to Piaget children up to the age of ten years operate within a system of external morality – rules are perceived as sacred and immutable and as extensions of authority figures. The child of this age does not believe he/she can change the rules in most situations.

Several studies have specifically tried to determine at what age children acquire social rules (Much & Schweder, 1978; Damon, 1977; Turiel, 1977). These studies have found that children as young as two years can develop an understanding of when rules have been broken. Later, between the ages of six to ten years children come to understand the importance of rules because they recognize their social function in maintaining order. Their understanding of rules is still limited to reasonably concrete, physically real situations.

Once past the period of concrete operations, approximately eleven years, children begin to understand that rules can be changed so long as there is a consensus. They can work on abstract principles and are willing to consider hypothetical problems.

In returning to the direct issue of teaching children safe hygienic procedures, the literature on the development of rule governed behaviour thus supports quite strongly the notion that children do not have to understand the issues at stake in order to learn to behave safely in such situations. The age at which a child would be able "to understand the need to avoid exposure to blood and body fluids containing blood" depends on the definition of "understand", but understanding in even the most concrete and elemental forms will develop much later than the age at which it would be possible to obtain compliance with a set of rules for precautionary behaviour.

To use an everyday example, children between the ages of two and four in our culture are routinely taught by their parents to wash their hands after using the toilet or before meal time. They comply with this rule because of the direct consequences imposed by their parents – praise if they comply and punishment if they do not. At this young age their behaviour is not driven by the motivation to avoid infection. In fact, many parents may themselves be following social convention by having their children wash their hands as opposed to a true appreciation of the role this behaviour has in reducing the risk of infections.

The fact that parents of young children (aged three to fours years) are typically aware of the need to teach their child safe hygienic practices, such as handwashing or using a Kleenex to blow their nose or not to spit at other children, means essentially that it is only a broadening of these practices to include protection against exposure to blood that needs to take place. What the AIDS epidemic has meant is that there is now an increased awareness of the fact that blood can be a carrier of pathogens. This fact is not new, but it has obviously taken on increased importance with the discovery of the human immunodeficiency virus. Parents need to be made aware of this fact so that they can include one more rule when teaching their children i.e., you wash yourself after using the toilet, before meal times, *and if blood, saliva, or nasal mucosa gets on your skin*. Because of the young age of the children, it would be better to include saliva and mucus as absolutes, rather than attempt to teach the difficult distinction of body fluids containing blood versus those that do not. Consideration of appropriate teaching strategies will be more fully discussed in the next section.

Making parents aware of this precaution and to have them begin to introduce it to their children at the earliest possible age is important for two reasons. First, even young three to four year old children can potentially encounter situations where hygienic practices would be vital to follow. Many young children spend part of their day with peers or in pre-school or day care programs where they may be exposed to blood or body fluids containing the human immunodeficiency virus. For this reason two reports (Aronson, 1987; Black, 1986) have already noted the need to develop policies concerning hygienic practices in pre-school and day care settings.

Secondly, there is the issue of obtaining compliance with a learned rule. Quite simply, understanding a rule or even the need for a rule is not the same as complying with the rule. It must be recognized that even adults who understand the risks of AIDS in terms of abstract concepts such as death, may still fail to comply with precautions. The issue of compliance is not synomous with the issue of understanding. It will never be possible to obtain 100% compliance in the general population either through rational explanations or other techniques. As Socrates said, "Knowledge is not virtue"!

A number of studies have examined the issues involved in obtaining compliance – compliance to general social rules as well as compliance to specific medical treatments or procedures. This research draws heavily from the area of behavioural psychology, a theoretical framework that emphasizes the importance of consequences in determining the frequency of a given behaviour. There is a considerable body of research which supports the value of behavioural techniques for promoting compliance (Bandura, 1969; Forehand & McMahon, 1981). The success, however, of behavioural techniques often depends on the attitudes of the parents and obtaining *parental compliance* is the key to the success of many programmes aimed at children (Becker, Drachman, & Kirscht, 1972; Pratt, 1973). This is amply demonstrated in recent studies (Roberts & Layfield, 1987; Roberts and Turner, 1986) that have examined programs designed to increase the compliance of young children to wearing automobile seat belts.

To summarize the point, if instruction is limited solely to didatic instruction in school settings without parental involvement, it is quite likely that future compliance to such precautions by the children will be much reduced. Parents of preschool aged children need to know the importance of washing after exposure to blood or body fluids containing blood so that they can protect themselves and play an integral role in the instruction of their children. When the children are older (aged five to seven), they can begin receiving the background material which will produce an "understanding" of why the rules governing safe hygienic practices are so important. As with other health education curriculum it is expected that the information would be reasonably factual and concrete for the younger grades and increasingly more detailed and abstract at the older grades.

Basic teaching strategies

The strategies that would be used to teach children to wash their skin on exposure to blood or bodily fluids would generally be dependent on their age. In this section we first discuss strategies that might be appropriate for very young children (ages three to four years) and then for older children (five to seven years). At the end there are some general observations that are applicable to all ages.

1. *Teaching the young child.* As discussed in the previous section, the starting place for instruction with young children is by educating their parents about the need for expanding the practice of hygienic washing to include situations where blood or bodily fluids might be involved. It is expected that this information would then be incorporated into everyday parent-child interactions. It may be important and appropriate for the parents to use the colloquial terms for saliva and nasal mucosa with which their child is already familiar.

In this regard it is important to note the role that effective discipline procedures would play in the acquisition of safe hygienic practices by young children. Young children learn to follow certain rules of behaviour as a result of the direct consequences for those behaviours imposed by their parents. Effective discipline involves positive rewards and praise for desireable behaviours, non-physical forms of punishment for non-compliance, clarity and simplicity of instruction, and consistency in application. Ross Parke (1977) has summarized the results of laboratory and naturalistic studies on discipline and cites five criteria: 1) promptness of rewards and negative consequences, 2) punishment must neither be too strict or too lenient, 3) punishment is more effective from a person on good terms with the child, 4) explanations should accompany the discipline but must be simple and age appropriate, 5) consistent punishment is effective. Other researchers such as Forehand & McMahon (1981) and Patterson (1982) essentially support these positions.

Additionally, young children learn from modelling behaviour that they see around them. While parents are the most important role models, young children could also learn from watching short advertisements or scenes on T.V. programs that would have various characters (real, animated, or puppet) following safe hygienic practices. In this case the young child would see that other people wash their skin after being exposed to blood or bodily fluids. The "scripts" for such scenes would have to be carefully composed, but the effects of modelling on the behaviour of young children should not be underestimated.

2. *Teaching the older child.* For the older child didatic instruction becomes a viable option. Similar to the way health instruction is currently taught in the schools, cuuriculum could be designed that would incorporate the new importance attached to washing the skin upon exposure to blood or bodily fluids.

It should also be possible to approach the problem by encouraging children to conform to scripted roles. Children typically learn how to behave for familiar events and routines such as shopping, going out in the car, playing games, preparations for bed, etc. A script includes roles, props, and expected actions. Children learn scripts for repeated events in their lives at the same time as they learn about the people in their lives. Thus, at about age four years children understand how two or three social roles fit together and as a result can engage in cooperative games such as playing "house". By age six years children understand how a much larger network of roles work together (Watson, 1981). By age six or seven children spend more time with other children and are more skillful at understanding another child's perspective. They begin to understand social rules and how to follow them. Thus, by age six or seven children would be able to benefit from the opportunity to practice the roles associated with precautionary measures. The didatic curriculum could be made more effective by including oppportunities for the children to practice "role playing" the important precautionary measures.

3. *General observations.* While the AIDS epidemic has heightened the awareness of the need to follow good hygienic practices, it is important to stress that good hygienic practices should be practiced by children regardless of the concern about AIDS. Particularly for young children (aged three to four years) it may even be counterproductive to place instruction in the context of AIDS. Thus, if parents placed too much emphasis on the "prevention of AIDS" in their interactions with young children, they may have the effect of producing unwarranted fears in their children. Children at that age will not be able to understand the abstract concepts of infection, risk reduction, and the AIDS epidemic. Parents do not routinely emphasize the problem of infection now when they tell children to wash their hands before dinner, nor do we see that changing when the set of precautions is broadened to include washing the skin after exposure to blood or bodily fluids.

Also, we note that the distinction between bodily fluids and bodily fluids containing visible blood is likely to be a particularly difficult one for children. It would appear to us prudent, therefore, to avoid this distinction, particularly when working with young children. It would be easier for children to learn an "absolute" rule that: "*when they get blood, saliva, or nasal mucus on them from another child or adult, they should wash the exposed area so that they can keep feeling healthy and strong*". Although exposure to body fluids without visible blood poses no risk for HIV infection we feel that by making the rule more general we will not only serve to reduce confusion for children but also promote hygienic practices that would help to reduce the risk of infection from more common pathogens.

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A Study of Attitudes and Beliefs About AIDS in Nova Scotia
for the Nova Scotia Task Force on AIDS

Prepared by

Decima Research Limited

1988

The opinions expressed in this paper are solely those of the author and should not be attributed to the Nova Scotia Task Force on AIDS.

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I. INTRODUCTION

Decima Research is pleased to submit this study of Nova Scotians' attitudes and beliefs about AIDS as a health issue in the province, to the Nova Scotia Task Force on AIDS.

The objectives of the study are:

- To examine perceptions of AIDS as a health threat relative to the extent of risk, beliefs about transmission and prevention, and concerns about the social impact of the disease;
- To identify sources of information about AIDS and assess levels of satisfaction with the reliability and quality of media coverage;
- To seek views on the responsibility of government vis à vis individuals at risk and protection of the general public;
- To examine issues regarding AIDS and the school system;
- To explore public perceptions of policy options for the treatment and prevention of the disease, and for care of AIDS carriers; and
- To assess perceptions of the way AIDS affects life-styles and sexual preferences.

The analysis presented in this report is based on data gathered from a sample of 600 residents of Nova Scotia, 18 years of age and older. The sample frame provides a sufficient number of cases to be accurate with ±4.1%, 95 out of 100 times.

The report is composed of six sections. Following the Introduction, Section II presents an analysis of general perceptions of AIDS as a health issue and discusses the implications of the findings relative to risk, beliefs about transmission and prevention, as well as the basis of concern about the social impact of AIDS. Section III explores priorities for an AIDS policy for the workplace, for landlords and tenants, and for the health profession. While the fourth section assesses perceptions of AIDS and the school system, Section V probes Nova Scotians' views on sources of information. Section IV discusses changes in people's life-styles as a result of AIDS, and the final section provides conclusions and recommendations.

II. NOVA SCOTIANS' PERCEPTIONS OF AIDS AS A HEALTH ISSUE

A. Most Important Health Issue

Nova Scotians are deeply concerned about AIDS. Almost half of those who were interviewed in this study identify AIDS as the most important health issue in the province today (see Table 1). This finding is particularly significant since responses to the question were not prompted by the interviewer. Clearly no other health issue is being perceived to be as pressing as is AIDS.

Table 1

MOST IMPORTANT HEALTH ISSUE IN NOVA SCOTIA

	PERCENTAGE
AIDS	46
Quality of the medical profession	1
Abortion	1
Aging population	1
Funding for health care	1
Other	41

High levels of public anxiety about AIDS may be attributable to the belief that AIDS is a fatal and incurable disease that is highly contagious (see Table 2). Moreover, people believe that AIDS is sexually transmitted and, although they do identify AIDS with homosexuals, they are apparently of the opinion that sexual encounters of all kinds are the main sources of transmission for the disease. AIDS is, therefore, seen to be a significant health threat to residents of Nova Scotia, with 87% of respondents believing AIDS is a very serious threat. Virtually no one is prepared to dismiss the disease as being unimportant and indeed only about 13% refer to it as being not too serious (see Table 3). Those who do think of AIDS as not too serious include people who may be among the most informed individuals in the province -- employed males, higher income earners, people with university level education, people who are in their late 20's to early 40's, married people with children, and residents of the Valley. In other words, these people are more likely to dismiss the high level of concern about AIDS. We are not yet able to offer conclusions about the basis for their different views, except to speculate that this group may include people who do not believe themselves to be personally at risk of contracting the disease.

Table 2

BEST WAY OF DESCRIBING AIDS

	PERCENTAGE
Deadly/fatal/incurable	60
Sexually transmitted	21
Frightening	11
Homosexually transmitted	7
Contagious/communicable	8

Table 3

AIDS AS A HEALTH THREAT

	PERCENTAGE
Not at all serious	1
Not too serious	12
Serious	42
Very serious	45

B. Individuals at Risk

A majority of Nova Scotians agree that AIDS is more likely to put some individuals in society at more risk than others. There is little doubt that most people believe homosexuals and the sexually promiscuous are the most likely to catch the virus. There is a weak tendency for females and members of lower socio-economic groups to associate the risk of contracting AIDS with anybody who is sexually promiscuous. On the whole, however, Nova Scotians believe AIDS is a greater health threat to homosexuals than to the rest of society (see Table 4).

Table 4

WHO IS MOST LIKELY TO CATCH AIDS

	PERCENTAGE
Homosexuals	63
Sexually promiscuous	13
Young people	9
Drug users	7

At the same time, there is absolutely no suggestion that AIDS carriers should be treated any differently than other terminally ill people. A majority (69%) do not believe that AIDS can be cured if treated early, although about one-in-five people indicate they are not sure if AIDS victims can be cured by early diagnosis and treatment. While the data show a strongly held belief that if a cure is ever found, it will not happen overnight, there is a highly evident belief in scientific solutions to society's problems. Very few people are prepared to say a cure will never be found for AIDS, just that it may take some time to achieve this cure.

Beliefs about the time frame for an eventual cure for AIDS depend on whether people perceive that early treatment of the disease makes any difference to the eventual cure, and on how seriously the disease itself is being taken (see Table 5). Those who are most confident about treatment and those who do not believe AIDS is a very serious health threat are more likely to believe that a cure will be developed within the foreseeable future. On the other hand, those who are most pessimistic about early diagnosis and treatment of the disease, and those who view AIDS as a "very serious" health threat in Nova Scotia are inclined to take a longer term view of an eventual cure for the disease. However, there are few significant demographic exceptions to this trend. Members of high-income groups are more inclined than most Nova Scotians to believe that early treatment of AIDS does not matter to an eventual cure and that a cure will be found in a relatively shorter time frame.

Table 5

WHEN AIDS WILL BE CURED BY BELIEFS ABOUT THE DISEASE

	2-5 YEARS %	6-10 YEARS %	10+ YEARS %	NEVER %
AIDS CURED IF TREATED EARLY				
Yes	44	35	15	8
No	29	31	22	12
Not sure	40	26	17	8
AIDS AS HEALTH THREAT				
Not serious	37	30	16	11
Serious	37	34	17	6
Very serious	28	27	24	15

C. How AIDS Carriers Should be Treated

Nova Scotians' concerns about AIDS as a health threat has not influenced the way they think society should treat AIDS carriers. Most respondents exhibit a belief in fair treatment for AIDS victims; only about one-quarter of those interviewed believe that AIDS carriers should be treated any differently than anybody else. Nevertheless, the data also show there is a core of people who may be described as "hard liners" who show consistently negative assessments of the way persons with AIDS should be treated. These attitudes lie at the root of their opinions on several issues to be considered in the study. In this context, hard liners are most likely to be males, senior citizens, people with less than high school education, residents of the South Shore and Valley regions, and people who live in small towns or population centres of under 100,000 people.

In summary, people believe AIDS is a significant health threat in Nova Scotia today and express a good deal of concern about it as a health issue. AIDS is perceived to be a problem for everyone in Nova Scotia, especially since everyone is at risk and the chances of finding a cure for the disease in the near future are seen to be slim. However, particular groups -- homosexuals and the sexually promiscuous -- are seen as more likely to be at risk. Despite the seriousness of the problem, there is a strongly held belief that AIDS victims should not be treated differently.

Table 6

SHOULD PERSONS WITH AIDS BE TREATED DIFFERENTLY*

	YES %	NO %
TOTAL	27	70
SEX		
Male	32	65
Female	22	75
AGE		
18-24	24	73
25-34	24	73
35-44	22	77
45-54	33	61
55-64	29	68
65+	42	54
EDUCATION		
Public/elementary	35	63
Some high school	28	67
Graduate high school	29	70
Vocational/technical	28	69
University	19	77
At school	22	73
REGION		
Halifax	22	75
South Shore	34	63
Valley	34	64
Northumberland	26	70
Cape Breton	25	71

* "No Opinion" was removed for clarity.

D. Attitudes Toward Transmission and Prevention of AIDS

Nova Scotians believe that AIDS is transmitted primarily by sexual contact, but a large number also believe that the AIDS virus can be caught through blood transfusions (see Table 7). Moreover, people are apparently making a distinction between the use of drugs by contaminated needles, relative to the normal process of blood transfusions that occur in a clinical setting. Body fluids (e.g. saliva, urine) are also mentioned frequently as a source of transmission (e.g. through cuts, sores and scratches), but by far the most frequent first mentions have to do with sexual relations.

Table 7

MAIN WAYS TO CATCH THE AIDS VIRUS
(THREE ACCEPTED RESPONSES - RANK ORDERED)

	PERCENTAGE
Sexual relations (Hetero - Homo)	88
Blood transfusions	61
Drugs and needles	31
Body fluids	19
Cuts, scratches, sores	10

Note 1: Question read: "What do you think are the main ways that someone could catch the AIDS virus?"

2: Miscellaneous, other and no responses removed.

People also believe that a person who has the AIDS virus may pass it on despite the fact that the carrier may have no symptoms of the illness; however, these beliefs tend to vary by socio-demographic characteristics. Most likely to believe that the virus is passed on without the carrier's as having any observable symptoms are people under 35 years of age, higher income earners, people with a university education or those at school, single or people living in common-law arrangements with children, employed females, and residents of the Halifax region. It should be noted, however, that a majority in every segment of the population report that they have made no changes in the way they live because of concern about the AIDS virus and how it may affect them.

When asked specific questions about how AIDS is transmitted, most Nova Scotians link the virus with sexual activity and somewhat surprisingly with donating blood (see Table 8). Quite clearly, casual contact, which may occur through children's play, food preparation and shared office equipment, is perceived as a less dangerous source of infection than is sexual contact. In fact, a large majority of respondents indicate they strongly believe medical experts' opinions (31% very strongly) that the AIDS virus cannot be transmitted by casual contact. Nevertheless, about half of these people also say they would be somewhat to very concerned about catching the virus if they were to have casual contacts with known carriers.

Table 8

BELIEFS ABOUT HOW AIDS
IS TRANSMITTED -- RANK ORDERED

	AGREE %
Sex with a man who is infected with AIDS	99
Sex with a woman who is infected with AIDS	98
Donating blood	47
Children playing with another child who is infected	29
Eating food prepared by someone who is infected with AIDS	22
Sharing office equipment with an infected co-worker	12

These findings suggest that there is still a good deal of uncertainty in people's minds about the disease and how the virus itself is being transmitted. Some people are deeply concerned about casual contact despite medical reassurances to the contrary. The general anxiety expressed about the potential health threat of AIDS in Nova Scotia is perhaps directly linked to a fear that not enough is known about the disease to offer definitive information to allay this deep sense of concern. People may appear to believe medical authorities, but they cannot quite put aside their apprehension about the unknown dangers of the disease. In any case, people who are most strongly concerned by the information put forward by medical experts are the least likely to be concerned about having casual contacts with known AIDS carriers. Others who are unconvinced by medical arguments show higher levels of concern about catching the virus (see Table 9). Moreover, the data show that these views are likely to affect the way they believe AIDS carriers should be treated by society. They are more likely to believe that AIDS carriers should be treated differently than should other terminally ill patients because these carriers can pass on the disease in any form of day-to-day contact. In-depth demographic analysis also reveals that certain segments of the population remain less convinced by medical experts than do others. In particular, males, senior citizens, and residents of rural areas in general and the South Shore in particular are more likely to indicate their disbelief that AIDS cannot be spread through casual contact.

Table 9

COMPONENTS OF CONCERN ABOUT THE TRANSMISSION OF AIDS
THROUGH CASUAL CONTACT*
(RANK ORDERED)

	CHI SQUARE X^{2*}
Concern about infection from casual contacts	143.3
Infection by children's play	62.7
Infection by donating blood	24.5

*X^2 (Chi Square) Association between belief in medical experts about transmission of AIDS through casual contact and forms of casual contact considered dangerous. All associations reported at .01 level of significance.

III. PRIORITIES FOR AN AIDS POLICY

A. AIDS and the Workplace

The high level of concern expressed about AIDS as a health threat to Nova Scotians does not extend to specific areas of life such as the workplace. Less than one-third of respondents indicate they are concerned about the possibility that someone they work with might have AIDS. Moreover, even when the potential threat of infection at work is personalized, such as in a job where the individual might be exposed to the virus through contact with blood or other bodily fluids, but where proper infection control procedures were used, a majority of respondents (65%) say they would be confident of not catching the virus. In fact, less than 20% express any real fear about becoming infected. Those who do express any tend to be people who do not believe medical experts' arguments and who are somewhat to very concerned that AIDS can be transmitted through casual contacts.

Despite no evidence of real concern about AIDS at the workplace, it is equally clear that Nova Scotians wish to see policies put into place which will protect them. Most respondents believe the main purpose of an AIDS policy should be to protect employees without AIDS rather than to protect the interests of employees with AIDS. Moreover, at least half of those interviewed believe that an employer should be able to require that the job applicant undergo a test for AIDS before being hired. This is also true if the person seeking the job is suspected of being a homosexual. But it is important to note that feelings about testing are the same regardless of any suspicions an employer may have about the sexual preferences of the prospective employee. In other words, people who believe that the employer should be able to require that an AIDS test be done believe it should be done regardless of sexual preference (Table 10).

Table 10

AIDS AND THE WORKPLACE

	YES %	NO %
Should employers require AIDS tests before hiring anyone	50	43
Should employers require AIDS tests before hiring homosexuals	54	43
Should employers fire employees with AIDS	22	75
Should co-workers be informed of AIDS carriers	68	29

Indeed, there is evidence of a strongly held desire to be fair and to not discriminate against fellow workers because of homosexuality or illness. Just as we have seen that Nova Scotians believe persons with AIDS should not be treated differently from other terminally ill patients, so we find a belief that no employer should have the right to fire a person with AIDS if there is no risk of exposure to infection for fellow workers. On the other hand, people are concerned about being protected and while they do not expect the employee with AIDS to be mistreated, they feel they have the right to know if a co-worker is infected (Table 10). Thus, we have sufficient evidence to conclude that Nova Scotians do not wish AIDS carriers or anyone else to suffer discrimination at work because of the employer's concern about AIDS. They are anxious that the steps taken must primarily be put in place to protect the workplace from the spread of the disease and not to victimize individuals. It is worth noting, however, that these beliefs are being influenced by demography. A critical variable is age. People who are 45 years old and older believe that AIDS testing for job applicants should be mandatory. There are also significant rural-urban differences of opinion with strongly held beliefs about mandatory AIDS tests and firing for those infected with the AIDS virus. These beliefs are most common among people with limited education, people over 55 years old, housewives, and among residents of the South Shore. These attitudes are also influenced by a disbelief in the medical view that AIDS cannot be transmitted by casual contact. On the other hand, attitudes toward a workplace policy regarding AIDS are not being significantly influenced by beliefs about whether testing for the AIDS virus should be mandatory or voluntary. Nova Scotians believe that testing should be voluntary, but even those who believe that testing should be mandatory do not endorse discriminatory policies at work.

B. AIDS Policies for Landlords and Tenants

The fair-minded attitudes toward AIDS carriers which we have seen in relation to the workplace extends as well into landlord-tenant relationships. Nova Scotians do not believe that a landlord should be able to refuse to rent to a potential tenant who is a carrier of the AIDS virus. In fact, most would not be concerned at all to know about fellow tenants who are carriers of the virus. Only 13% say they would move out of the building. Many people, however, would not continue to share common facilities such as the laundry with AIDS carriers. It would therefore be wrong to conclude that people would be unconcerned about living with AIDS carriers. They would obviously limit their contacts to the superficial, but they would not be so concerned about catching the virus that they would move out of the building (Table 11).

Table 11

RENTING AND AIDS CARRIERS

	YES %	NO %
Should a landlord refuse to rent	18	78
Should other tenants know of the carrier	39	60

HOW WOULD YOU ACT IF A KNOWN CARRIER WERE LIVING WITH YOU?

	PERCENTAGE
Move out	13
Remain but not share facilities	41
Continue to share facilities	43

When asked whether they believe that to control the spread of diseases like AIDS, it is necessary for all AIDS carriers to be separated from the general population, only 18% agree. About 81% say they believe that if other infection control procedures are followed, carriers are not a threat to the general population of Nova Scotia. These answers are obviously indicative of the widespread belief that the virus is spread by intimate contact and that people do not feel threatened where they live. Yet quite clearly the views are not shared by everybody. People who believe that AIDS carriers should be treated differently also believe that AIDS is spread by casual contact; thus they support the landlords' right to refuse to rent to AIDS carriers. Once again, these people tend to be older (55+ years), members of lower socio-economic groups, residents of rural areas and, in particular, residents of the South Shore region of the province.

C. AIDS Testing and the Right to Know

We have seen that a majority of Nova Scotians believe that testing for the AIDS virus should be carried out on a voluntary basis only (Table 12). However, it is also clear that people believe they have the right to protection, and government has been identified with that responsibility. Therefore, it is not surprising to find a strong belief in the need to know when individuals test positive for the virus. There are no expectations that individuals' rights must be violated in the public interest. Rather, Nova Scotians think that it is public officials who must be informed of the results of the test. Only 18% of respondents say the general public has the right to know when an individual tests positive.

Table 12

SHOULD AIDS TESTS BE MANDATORY OR VOLUNTARY IN NOVA SCOTIA

	PERCENTAGE
Mandatory	33
Voluntary	65
HOW CONFIDENT TESTS WOULD REMAIN PRIVATE	
Not at all	23
Not too	35
Somewhat	27
Very	14

At the same time, there is genuine concern about confidentiality. Almost a quarter of those interviewed say they are not at all confident that the results of the tests would remain confidential, and 35% say they are not too confident. In spite of beliefs that public health officials should know, many Nova Scotians do not trust these officials to keep the information confidential. Surely this suggests a deep concern about the match between public health priorities and individual rights. Indeed, most people have never discussed the spread of AIDS with their doctors! These data lead us to conclude that people who are concerned about having been exposed to the virus may be very timid about coming forward to present those concerns to their family doctors, because they do not entirely trust the confidentiality they will receive from the health care system.

Confidentiality does not extend to concealing the existence of an infection from sexual partners. Virtually everyone agrees that partners of infected persons should be traced and warned that they might have been exposed to the AIDS virus. However, it is officials from the Department of Health and not doctors who are perceived to have the main responsibility for tracing and informing the partners.

Thus we note there are concerns about the confidentiality of AIDS tests. Most people believe that mandatory testing could result in violations of individual rights. At the same time, there is still a strongly held belief in public protection where health authorities are believed to be best able to ensure that appropriate measures are taken to control the spread of the disease once the carrier has been identified.

D. Spending Priorities

As far as expenditures of taxpayers' dollars on AIDS is concerned, once again it is clear that Nova Scotians would prefer to see government direct their funds to the protection side rather than to treatment (Table 13).

Table 13

PRIORITIES FOR SPENDING ON AIDS (RANK ORDERED BY PERCENT VERY IMPORTANT)

		PERCENTAGE
1.	Medical research	92
2.	Public education	88
3.	Testing facilities	74
4.	Counselling for patients	66
5.	Home care for patients	52
6.	A hospital for dying patients	51

Research, education and testing are considered to be more important than patient-oriented services. It is not that people consider the patient to be expendable, but that their concerns are with the spread of the disease itself, rather than with the individual who have it. The overwhelming number of respondents who describe this as being very important is highly indicative of the value placed on government action. There are few demographic exceptions to this overall pattern of findings, which would lead us to conclude anything but that Nova Scotians want their money spent on their own protection.

IV. AIDS AND THE SCHOOL SYSTEM

A. Risks At School

One of the main objectives of this study is to examine public attitudes toward carriers of the AIDS virus. In a public opinion climate characterized by heightened anxiety about the amount of attention being directed at protecting the public from the spread of AIDS, the threat posed by children in school coming into contact with persons who either carry the AIDS virus or who have been exposed to the AIDS virus, is particularly relevant. To assess this, respondents were asked if they would send their children to school with confidence, misgivings or not send their children at all, if individuals at school, including either teachers or fellow students, had been exposed to the AIDS virus (see Table 14).

Table 14

WOULD SEND CHILD TO SCHOOL WITH
CONFIDENCE, MISGIVINGS OR NOT AT ALL

		CONFIDENCE %	MISGIVINGS %	NOT SEND %
(I)	Teacher was a homosexual exposed to the AIDS virus	31	37	29
(II)	Teacher was a man exposed to the AIDS virus	38	36	23
(III)	Teacher was a woman exposed to the AIDS virus	39	35	23
(IV)	Another student was exposed to the AIDS virus through sex	30	45	21
(V)	Another student was exposed to the AIDS virus through other means	38	43	16
(VI)	Another student exposed to the AIDS virus through blood transfusion	40	41	15

The most obvious conclusion to be drawn from the data is that despite a strong desire to be fair and a widespread belief that the AIDS virus cannot be transmitted by casual contacts, Nova Scotians are not prepared to take chances with their children. While few people indicate they would not send their children to school at all, many would do so with misgivings about their children's health, especially if they might come into contact with fellow students who had been exposed to the AIDS virus. This is not to suggest that teachers are not also suspect, since more people who would not send their children school at all identify their concerns about teachers rather than about students. Nevertheless, the fear of contact seems to revolve mainly around students.

Nova Scotians are clearly concerned by what they perceive to be a potential risk to their children, but when their own children are the carriers they would not only continue to send them to school, but expect other parents to continue to send their children to the same school with their infected children. In other words, fear in this context is selfish, it doesn't matter as much when it is somebody else's child who is at risk!

There are significant demographic differences on these attitudes; however, there is strong evidence to suggest that opinions are being influenced by how seriously a health threat AIDS is believed to be, as well as a belief that AIDS can be caught by casual contacts or by donating blood. These attitudes are also significantly associated with a belief that AIDS carriers should be treated differently than other terminally ill patients. That is to say, individuals who are opposed to any form of regular contact between AIDS carriers and the rest of society feel carriers should be treated differently. For other Nova Scotians, this may simply reflect uncertainty about whether to expose children to an unnecessary risk.

B. AIDS Education

There is overwhelming support for AIDS education programs being carried out in Nova Scotian schools. Moreover, there is virtual unanimity (90%) that these programs shall be mandatory. And, while opinions are somewhat divided about what grades they should begin, the most frequently mentioned school level is junior high school. It is interesting to note, however, that about 40% of respondents believe they should be conducted in elementary school and 5% identify primary school as an appropriate time to begin.

Table 15

GRADE WHEN EDUCATION PROGRAMS FOR AIDS SHOULD BEGIN

	PERCENTAGE
Primary	5
Elementary	40
Junior high	52
High school	2

It goes without saying that Nova Scotians see the government as taking the lead in informing people about prevention. Thus, it would be the federal and provincial Departments of Health which would be expected to take the lead in organizing the contents of the program.

In this chapter we have examined questions relating to AIDS and the school system. We have found that Nova Scotians are anxious about their children coming into contact with people exposed to AIDS while at school. People who are uncertain about casual contacts between their children and AIDS carriers are likely to resist the presence of infected individuals in the school system. Governments will be required to approach this attitude with caution, since these feelings may run counter to other beliefs about being fair which are easier to support in contexts, such as at the workplace or in an apartment building.

We have also found widespread support for mandatory AIDS education programs in the public school system. The government will have to consider this request carefully since the message is loud and very clear. It will be necessary to balance support for the education system with any heavy-handed action which is required to allay fears about exposure to the virus among children.

V. SOURCES OF INFORMATION ON AIDS

A. How People Get Information on AIDS

Respondents were asked to identify their best sources of information on AIDS. As we have seen above, people perceive provincial and federal health departments to have the main responsibility for informing people about preventing the spread of AIDS, but it is the media which ultimately provide the message upon which attitudes and opinions are formed.

Table 16 presents findings on how Nova Scotians receive information about AIDS. Not surprisingly, the most frequently mentioned sources are the media. Respondents identify television, newspapers and radio as the best places to get information on AIDS. They were encouraged to mention up to three sources and the table provides the three most frequent mentions. Respondents also identify family members, books, movies, health professionals or pamphlets, but do not describe them as being as informative as is television.

Table 16

THREE BEST SOURCES OF INFORMATION
(MOST FREQUENT MENTIONS - RANKED)

	% OF MENTIONS
Television	84
Newspaper	53
Radio	31
MOST RELIABLE SOURCE OF INFORMATION	
Television	45
Newspaper	11
Medical people	10
PREFERRED SOURCE OF INFORMATION	
Doctors and medical people	33
Television	29
Newspaper	8

In order to round out the picture, we also asked respondents to identify which information source they consider to be the most reliable and the source from which they prefer to receive information.

There is a strong correlation between the opinions which are being expressed about information sources (Table 16). Television is the medium by which people in Nova Scotia are being informed about AIDS, and people are looking more frequently and confidently to television for their information. However, they would prefer to hear more from their doctors and other medical people.

There are problems in these findings for the role of the medical profession in education about AIDS; they are simply being perceived as not having done enough. This, along with the finding that only 10% of respondents have even discussed AIDS with a doctor, suggests that people are concerned about how much information the medical profession is actually able to provide them about the problem.

Doctors then have credibility problems, which must be drawn to the attention of the medical profession.

B. The Quality of Media Coverage

Table 17 presents a summary of public opinions on current AIDS coverage in the media. The findings indicate that people are generally satisfied with the quality of media coverage and indeed that 43% of respondents believe it to be satisfactory. However, Nova Scotians are uncertain about whether there is enough coverage. About 42% think that there is not enough information being presented. This is entirely consistent with the high level of concern being expressed about AIDS as a health threat in the province; people are anxious and they want to know more.

Table 17

MEDIA COVERAGE OF AIDS

	PERCENTAGE
QUANTITY	
Not enough	42
About right	46
Too much	11
QUALITY	
Poor	14
Adequate	42
Good	43

In demographic terms, there are differences in the quantity of media coverage by socio-economic level. Higher socio-economic groups tend to believe that media coverage is about right, while people with lower education and income believe that the quantity of media attention could be increased. There are no other significant demographic differences.

In conclusion, we have found that governments, both federal and provincial, are believed to have the main responsibility for providing information to the public on AIDS. However our study shows that the role of government is perceived rather as a facilitator, and the media, particularly the television medium, is seen to be the most reliable and most often consulted source of information. On the whole, the assessment of media coverage is positive, but there is a belief that there could be more. The message is straightforward: the Task Force will not be criticized for increasing the amount of media coverage of AIDS receives. On the other hand, it is likely to find that television time will yield the most dramatic results and find widespread support from Nova Scotians. For the medical profession, the findings indicate that much more of its time and attention must be directed at providing advice and information to assuage the current state of anxiety.

VI. LIFE-STYLE CHANGES

A. Sexual Relations

The study has also examined ways in which AIDS is affecting sexual relations in Nova Scotia society today. Respondents were asked several questions about the way the spread of AIDS has changed their sexual habits. As we have already seen, 64% of people believe that AIDS will not influence the way they live their lives to any great extent. Almost 80% report that AIDS will not change their sexual habits very much or not at all. Only 10% suggest it might change their sexual habits a great deal. These people tend to be males, young people (18-24 years), single people without children, people in service occupations, and residents of Halifax.

The kinds of changes that people were asked to identify are relatively unimportant since so few people are likely to change their behaviour at all (see Table 18). The most frequently mentioned type of change is to become more cautious about with whom to have sex. Most would not reduce sexual partners or use condoms as a precaution, but they would apparently be more careful about the one partner they pick. This is most likely because a vast majority of respondents are in long-term monogamous relationships. It is therefore no surprise to find that most Nova Scotian do not feel they are at risk of contracting the AIDS virus.

Correlation analysis also shows that the homosexual is perceived to be at greatest risk from AIDS. Thus for the majority, the likelihood of catching the disease through their own sexual behaviour is perceived to be very remote. However, we have seen that Nova Scotians continue to define AIDS as a major health threat from which they demand protection. Despite reassurance to the contrary, AIDS has become defined as disease to which they can be exposed in hospitals or other clinical settings where blood is exchanged. There is a good deal of concern about being protected from its spread. However, it is not sexually based and the majority of Nova Scotians are not likely to change their sexual habits.

Table 18

AIDS AS SOURCE OF CHANGES IN SEXUAL HABITS

	YES %	NO %
Reducing the number of sexual partners	31	66
Becoming more cautions about sex	48	49
Start using condoms	30	67

VII. CONCLUSIONS AND RECOMMENDATIONS

In this study, we have seen that Nova Scotians perceive AIDS to be the number one health threat in the province. At the same time, they do not perceive themselves to be at great risk, certainly not enough to change their life-styles, how they interact at work or with whom they share accommodations. Nevertheless, there is a strongly held belief that they must be protected from the spread of disease. They do not wish AIDS carriers or even potential carriers, in this case defined as most likely to be homosexuals, to be singled out at work or otherwise treated unfairly by society. Yet, the people of Nova Scotia are sufficiently anxious about the spread of AIDS to them that they perceive that government should be doing something.

Once again, it is clear this does not extend to isolating AIDS carriers, or requiring mandatory AIDS screening for job applications. Nova Scotians expect more information on AIDS and greater efforts at educating people about how the disease is contracted and spread.

The onus seems to be on educational officials to ensure that children in school are adequately informed of the dangers posed by the disease. At the same time, it is clear that Nova Scotians do not necessarily want AIDS carriers in the same classrooms as their children. The boundaries of fairness do not apparently extend to any exposure of children to risks in the classroom.

Priorities for government spending are also protection-oriented rather than treatment-oriented. It would not be correct to assume that the carrier is considered expendable. However, the public places a higher priority on the protection of the public-at-large than of the individual who has the disease. Government will have to respond to these anxieties by announcements which are protection rather than treatment oriented, (e.g. research, education and youth counselling) as opposed to greater expenditures on hospital care for those with AIDS.

Indeed, the government will have to be seen to be fair and even-handed in their approach to the carriers of AIDS virus without the appearance of giving too much attention to them at the expense of public protection. Above all, Nova Scotians want protection in a context of fairness.

TECHNICAL APPENDIXES

APPENDIX

A. SURVEY OVERVIEW..26

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A. SURVEY OVERVIEW

Decima Research is pleased to present to the Nova Scotia Task force on AIDS, the results for this study.

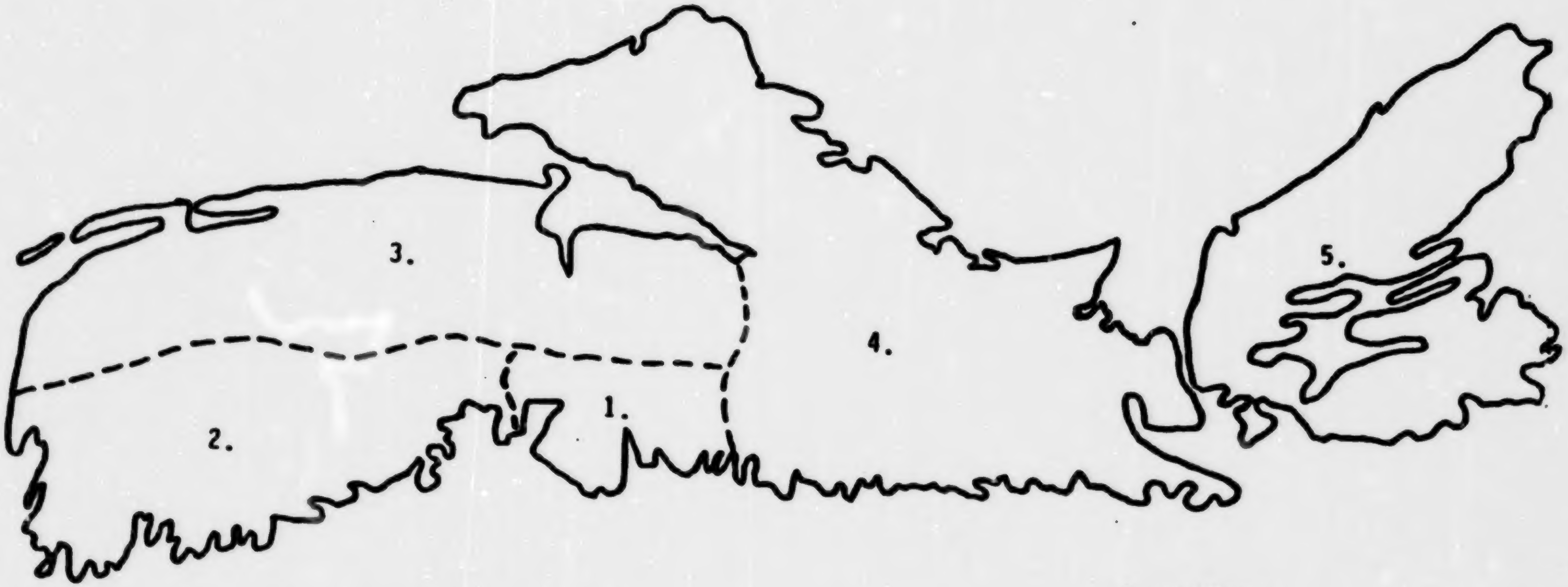
Senior Research Consultant and principal investigator for this study was Peter M. Butler, Ph.D. who was assisted in the various phases of research and analysis by Catherine Blewett, Jean Guy Banville and Linda Vignale.

1. Sample Selection

The population consists of all residents of Nova Scotia, 18 years of age and older. Male and female respondents were selected in the same proportion as the general population, on a 50/50 sex quota. A total of 600 interviews were completed.

Effective survey research must be based on a sample truly representative of the universe of interest. A multi-stage sampling technique was employed to gather the data for this study. The essential feature of this procedure is that individual respondents are predetermined by the selection procedure itself. That predetermination is made by careful speculation of a series of controlled choices.

The sampling technique produced a systematic random sample with probability of selection proportionate to size at the provincial level. The first step in the sampling procedure was the division of the province into five strata or "regions" (Table A). The definition of the boundaries for these regions is presented in the following map.



(not to scale)

1. Halifax
2. South Shore
3. Valley
4. Northumberland
5. Cape Breton

NOVA SCOTIA SAMPLING STRATA

Table A

SAMPLE STRATA

	PERCENTAGE OF POPULATION	PPS N (600)
REGIONS		
Halifax	32.7	196
South Shore	11.8	71
Valley	15.7	34
Northumberland	19.7	118
Cape Breton	20.2	121

Table A presents the percentages of the total population represented in each region, followed by the proportionate number of cases in each.

Within each of these regions, a sampling procedure was employed which is based upon mapping the linkage between the geographic location of individual telephone exchanges and Statistics Canada's fundamental building block for the census -- the enumeration area (EA).

Telephone companies divide their service regions into smaller areas served by a single switching centre. Within each switching centre area, all telephone numbers begin with the same two digits. We refer to these mutually exclusive exchange areas as NNXs (NNX representing the first three digits of a telephone number). Using census data, together with maps showing the geographic boundaries of NNXs, it is possible to determine exact population figures for each NNX and determine the appropriate number of respondents to be surveyed in each NNX.

Primary sampling units (groups of NNXs) and secondary sampling units (individual NNXs) were selected on the basis of probability proportionate to population size. Telephone numbers were then generated using a computerized random number generation program employing random start and fixed interval methods.

2. Field Procedures

The questionnaires were printed, consecutively numbered, and assembled into field packs of three interviews -- two males and one female or two females and one male. This procedure ensured that the 50/50 sex quota would be met by preselecting males and females before the interviewing began.

The interviews took place between March 5 and 22, 1988. Weekday interviewing was conducted between the hours of 5:30 and 10:00 p.m. and weekend interviewing between 10:00 a.m. and 5:00 p.m. The questionnaire contained 81 questions (including five open-ends) and took approximately 28 minutes to complete. Fifteen percent (15%) of all interviews were monitored while in progress for procedure and content from an extension monitor. All interviews were carefully edited as soon as they were completed to ensure that no questions were omitted and that skip-patterns were followed correctly.

Experienced telephone interviewers were used to collect the data. A briefing was held by the Field Supervisor to clarify procedures. The Field Supervisor first read the questionnaire to the interviewers, thereby ensuring that pronunciation would be correct and uniform, and second, interviewer-respondent role-playing was used to illustrate skip and rotation patterns. The interviewers then had an opportunity to ask questions.

All work was edited by the Senior Field Supervisor, checked for completeness, quality, and skip-pattern adherence. Then 15% of each interviewer's work was verified; that is, respondents were contacted by telephone and were asked to verify that the interview actually took place. Respondents were also asked to answer a few questions from the questionnaire in order to check the accuracy of the data collected.

3. Coding

The questionnaires were coded and the data were entered by experienced Decima personnel. The following standard procedures were followed:

- An initial briefing;
- Supervision of trained staff; and
- Verification of 15% of each coder's work.

Using the first 25% of completed questionnaires in each stratum, codes were constructed for the open-end questions by sorting and writing out the responses into independent categories. The Research Analyst checked all categories for completeness and consistency.

4. Data Processing

The entry and processing of the data were carried out on-site using Decima's Digital PDP 11/44 computer. Decima's interactive software system, designed specifically for survey analysis, has a robust data entry facility, which permits cleaning of the data, including out-of-range values and skip-pattern errors, as well as other logic errors. The fully cleaned data were then summarized into aggregate tables. Further analysis of the data included crosstabulation tables and measures of association.

5. Confidence Limits and Validation

The sample of 600 cases produces results which are accurate for the population of Nova Scotia as a whole within ±4.1 percentage points 95 out of 100 times.

In order to validate the sample, we compared our data for the age categories of the population with figures provided by Statistics Canada. Table B outlines the percentage of respondents in each age category for the sample, and the corresponding population figures. As these figures suggest, the sample drawn for this study reflects the more general characteristics of the adult population.

Table B

SAMPLE VALIDATION

AGE	SAMPLE (n=600) %	UNIVERSE[1] (N=642,880) %
18-19	4.5	4.5
20-24	8.7	12.7
25-29	12.4	12.1
30-34	13.4	11.1
35-39	15.4	10.6
40-44	10.9	8.2
45-49	7.9	6.7
50-54	5.9	6.2
55-59	6.5	5.9
60-64	4.5	5.8
65+	9.9	16.2

[1] Source: 1986 Census of Canada Catalogue 93-101.

It should be noted that age has been validated for Canadians who are 18 years of age or older. As well, the sample is only representative of residents in the provinces who have direct dialing telephone services. Therefore, Canadians who are accessible only by a telephone servicing a large number of people, such as senior citizen homes, hospitals, and Indian Reserves, and those who have only radio-telephone service or no telephone service at all, are automatically excluded from the sample. Any further questions the reader has about sampling should be referred to the Research Consultant.

While the most sophisticated procedures have been used to collect and analyse the information presented herein, it must be remembered that surveys are not predictions. They are designed to measure public opinion within identifiable statistical limits of accuracy at specific points in time. This survey is in no way a prediction of opinion or behaviour at any future point in time.

B. INTERVIEW SCHEDULE

A. Are you 18 years of age or older and a resident of Nova Scotia?

YES (CONTINUE)..A
NO (ASK TO SPEAK TO ELIGIBLE RESPONDENT, IF STILL "NO," THANK AND TERMINATE)..B

B. Have I reached you at your home phone number?

YES (CONTINUE)..A
NO (ASK TO SPEAK TO ELIGIBLE RESPONDENT, IF STILL "NO," THANK AND TERMINATE)..B

C. Do you, or does anyone in your family or household work in the following kinds of business...a market research firm, advertising agency, public relations firm, or the news media?

YES (THANK AND TERMINATE -- RECORD INCIDENCE ON CALL RECORD SHEET)...A
NO (CONTINUE)...B

We are doing this survey on a health topic that is very important to all of us, but which is also sensitive. Your responses are very important but if you feel uncomfortable about answering a question, we can skip it and go on to the next.

1. What is the most important health issue facing people in Nova Scotia today? (DO NOT READ LIST...ACCEPT ONLY ONE RESPONSE)

THE AGING POPULATION	1	(1%)
FUNDING FOR HEALTH CARE	2	(1%)
AIDS	3	(46%)
QUALITY OF THE MEDICAL PROFESSION (DOCTORS, NURSES)	4	(1%)
ABORTION	5	(1%)
OTHER	6	(41%)
NO OPINION (VOLUNTEERED)	7	(8%)

REFER TO APPENDIX C FOR COMPLETE VERBATIM RESPONSES

Note 1: Responses may not sum to 100% due to rounding throughout the Technical Appendixes.

2: (*) denotes a percentage value greater than 0 but less than 0.5 throughout the Technical Appendixes.

2. I'd like to get your opinion about one health issue. Over the last few years, there has been a lot of discussion about the disease known as AIDS. In your opinion, what would be the best way of describing the disease known as AIDS? (PROBE...ACCEPT UP TO THREE RESPONSES)

DEADLY/FATAL	01	(33%)
INCURABLE	02	(10%)
ATTACKS IMMUNE SYSTEM	03	(17%)
CONTAGIOUS/COMMUNICABLE	04	(8%)
SEXUALLY TRANSMITTED	05	(21%)
HOMOSEXUALLY TRAMSMITTED	06	(7%)
DRUG USE	07	(4%)
A VIRUS	08	(4%)
BLOOD TRANSFUSIONS	09	(2%)
BLOOD DISEASE	10	(3%)
SINFUL/UNNATURAL	11	(2%)
OTHER METHODS OF TRANSFUSION	12	(2%)
DANGEROUS/HAZARDOUS	13	(52%)
LIKE CANCER	14	(3%)
TERRIBLE/FRIGHTENING	15	(11%)
SOCIAL DISEASE	16	(2%)
EPIDEMIC	17	(3%)
DESTROYS THE BODY	18	(1%)
KNOWLEDGE/AWARENESS	19	(4%)
DISEASE	20	(2%)
CARRIERS NOT SHOWN SYMPATHY	21	(1%)
OTHER	22	(13%)
DON'T KNOW	23	(10%)
NO RESPONSE (VOLUNTEERED)	24	(3%)

REFER TO APPENDIX C FOR COMPLETE VERBATIM RESPONSES

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3. Overall would you say that AIDS represents a very serious, a serious, a not too serious or not at all serious health threat in Nova Scotia today?

NOT AT ALL SERIOUS	1	(1%)
NOT TOO SERIOUS	2	(12%)
SERIOUS	3	(42%)
VERY SERIOUS	4	(45%)
NO OPINION (VOLUNTEERED)	5	(*)

---

4. We would like to ask your opinion about how people get information on AIDS. As you may know, information relating to the disease is available through many different sources, ranging from the media, the family and the community. Which have been your best three sources of information? (DO NOT READ LIST PROBE...ACCEPT UP TO THREE ANSWERS)

RADIO	01	(31%)
TV	02	(84%)
MAGAZINES	03	(24%)
NEWSPAPERS	04	(53%)
PAMPHLETS	05	(12%)
BOOKS/JOURNALS	06	(8%)
VIDEOS/MOVIES	07	(1%)
SCHOOL	08	(6%)
PUBLIC HEALTH UNIT	09	(0%)
COMMUNITY GROUP	10	(4%)
MOTHER	11	(*)
FATHER	12	(*)
OTHER FAMILY MEMBERS	13	(3%)
FRIENDS	14	(7%)
NURSE	15	(1%)
DOCTOR	16	(12%)
CHURCH	17	(1%)
OTHER	18	(1%)
RED CROSS	19	(*)
PUBLIC MEETINGS	20	(1%)
WORK	21	(2%)
WORD OF MOUTH	22	(1%)
HOSPITALS	23	(1%)
DEPARTMENT OF HEALTH	24	(2%)
GOVERNMENT - GENERAL	25	(1%)
MEDIA	26	(1%)
NO OPINION (VOLUNTEERED)	27	(*)

5. Of the sources you have mentioned, which one would you say provides the most reliable information? (DO NOT READ LIST...ACCEPT ONLY ONE ANSWER)

RADIO	01	(3%)
TV	02	(45%)
MAGAZINES	03	(8%)
NEWSPAPERS	04	(11%)
PAMPHLETS	05	(6%)
BOOKS/JOURNALS	06	(4%)
VIDEOS/MOVIES	07	(1%)
SCHOOL	08	(3%)
PUBLIC HEALTH UNIT	09	(1%)
COMMUNITY GROUP	10	(2%)
MOTHER	11	(*)
FATHER	12	(0%)
OTHER FAMILY MEMBERS	13	(*)
FRIENDS	14	(1%)
NURSE	15	(*)
DOCTOR	16	(8%)
CHURCH	17	(*)
RED CROSS	18	(*)
PUBLIC MEETINGS	19	(1%)
WORK	20	(1%)
HOSPITALS	21	(1%)
MEDIA - GENERAL	22	(1%)
GOVERNMENT - GENERAL	23	(1%)
ALL OF THEM	24	(*)
NO OPINION (VOLUNTEERED)	25	(4%)

6. Which source would you prefer to find out about AIDS from? (DO NOT READ LIST...ACCEPT ONLY ONE ANSWER)

RADIO	01	(2%)
TV	02	(29%)
MAGAZINES	03	(4%)
NEWSPAPERS	04	(8%)
PAMPHLETS	05	(5%)
BOOKS/JOURNALS	06	(7%)
VIDEOS/MOVIES	07	(0%)
SCHOOL	08	(3%)
PUBLIC HEALTH UNIT	09	(6%)
COMMUNITY GROUP	10	(2%)
MOTHER	11	(*)
FATHER	12	(0%)
OTHER FAMILY MEMBERS	13	(*)
FRIENDS	14	(1%)
NURSE	15	(1%)
DOCTOR	16	(26%)
CHURCH	17	(0%)
RED CROSS	18	(*)
PUBLIC MEETINGS	19	(1%)
WORK	20	(*)
HOSPITALS	21	(1%)
MEDIA - GENERAL	22	(*)
GOVERNMENT - GENERAL	23	(2%)
ALL OF THEM	24	(*)
NO OPINION (VOLUNTEERED)	25	(4%)

7. We'd like to have your opinion on the coverage of AIDS in the media. In general, do you think there is too much coverage, that the coverage is about right, or that there is not enough attention given to AIDS?

NOT ENOUGH	1	(42%)
ABOUT RIGHT	2	(46%)
TOO MUCH	3	(11%)
NO OPINION (VOLUNTEERED)	4	(1%)

8. And what about the quality of media coverage...In general, do you think that media coverage is good, adequate or poor?

POOR	1	(14%)
ADEQUATE	2	(42%)
GOOD	3	(43%)
NO OPINION (VOLUNTEERED)	4	(1%)

9. In your opinion, are there some groups or individuals in society who are more likely to catch the AIDS virus than others?

NO (SKIP TO Q11)	1*	(15%)
YES (GO TO Q10)	2	(83%)
NO OPINION (VOLUNTEERED)	3	(2%)

IF "YES" TO Q9, ASK:

10. Which group of people do you think is most likely to catch the AIDS virus? (PROBE...ACCEPT ONLY ONE RESPONSE...ANSWER MUST BE AT LEAST TEN WORDS)

HOMOSEXUALS	01	(63%)
SEXUALLY ACTIVE/PROMISCUOUS	02	(13%)
DRUG USERS	03	(7%)
YOUNG PEOPLE	04	(9%)
STREET PEOPLE	05	(1%)
IMMORAL/OUT GOOD TIME	06	(*)
HEMOPHILIACS	07	(1%)
ANYONE	08	(1%)
OTHER	09	(3%)
DON'T KNOW	10	(2%)
NO RESPONSE (VOLUNTEERED)	11	(1%)

REFER TO APPENDIX C FOR COMPLETE VERBATIM RESPONSES

11. Do you think AIDS can be cured if treated early?

YES	1	(9%)
NO	2	(69%)
NOT SURE/DON'T KNOW (VOLUNTEERED)	3	(22%)

12. Should persons with AIDS be treated differently from other terminally ill patients?

YES	1	(27%)
NO	2	(70%)
NO OPINION (VOLUNTEERED)	3	(3%)

13. We'd like your opinion on how close researchers are to finding a cure for AIDS. Would you say there is likely to be a cure found in the next two years, in three to five years, in six to ten years, that it will take more than ten years, or do you think that there will never be a cure for AIDS?

NEXT TWO YEARS................	1	(4%)
THREE TO FIVE YEARS...........	2	(29%)
SIX TO TEN YEARS..............	3	(30%)
MORE THAN TEN YEARS...........	4	(20%)
NEVER.........................	5	(11%)
NO OPINION (VOLUNTEERED)......	6	(6%)

And we would like to ask you some questions about AIDS and the workplace.

14. How concerned are you about the possibility that someone you work with might have AIDS?

NOT CONCERNED AT ALL..........	1	(35%)
NOT VERY CONCERNED............	2	(24%)
SOMEWHAT CONCERNED............	3	(16%)
VERY CONCERNED................	4	(13%)
NOT EMPLOYED (VOLUNTEERED)....	5	(11%)
NO OPINION (VOLUNTEERED)......	6	(1%)

---

15. If you worked in a job which might involve contact with blood or other bodily fluids, but where proper infection control procedures were used, how confident would you be that you would not catch the AIDS virus?

NOT AT ALL CONFIDENT..........	1	(16%)
NOT CONFIDENT.................	2	(17%)
SOMEWHAT CONFIDENT............	3	(36%)
VERY CONFIDENT................	4	(29%)
NO OPINION (VOLUNTEERED)......	5	(2%)

---

16. What, in your opinion, should the main purpose of an AIDS policy in your workplace be: (ROTATE) to protect employees without AIDS or to protect the interests of employees with AIDS?

WITHOUT AIDS..................	1	(65%)
WITH AIDS.....................	2	(19%)
NO OPINION (VOLUNTEERED)......	3	(17%)

17. Let us say that a person is applying for a job. Do you think that the employer should be able to require that the job applicant undergo a test for AIDS before being hired?

YES	1	(50%)
NO	2	(43%)
REFUSED (VOLUNTEERED)	3	(3%)
NO OPINION (VOLUNTEERED)	4	(4%)

---

18. Let us say that a person, who is suspected of being a homosexual, is applying for a job. Do you think that the employer should be able to require that the job applicant undergo a test for AIDS before being hired?

YES	1	(54%)
NO	2	(43%)
REFUSED (VOLUNTEERED)	3	(2%)
NO OPINION (VOLUNTEERED)	4	(2%)

---

19. If an employer learns that an employee is infected with the AIDS virus, and none of the employee's work exposes co-workers to infection, do you think the employer should have the right to fire the person?

YES	1	(22%)
NO	2	(75%)
NO OPINION (VOLUNTEERED)	3	(4%)

---

20. If an employer learns that an employee is infected with the AIDS virus and does not fire the person, should co-workers be informed that the person is a carrier of the AIDS virus?

YES	1	(68%)
NO	2	(29%)
NO OPINION (VOLUNTEERED)	3	(4%)

---

21. If a landlord finds out that a potential tenant is a carrier of the AIDS virus, do you think that the landlord should be able to refuse to rent the apartment to them?

YES	1	(18%)
NO	2	(78%)
NO OPINION (VOLUNTEERED)	3	(4%)

---

22. If a landlord does rent to a tenant who is a carrier of the AIDS virus, should other tenants be notified?

YES	1	(39%)
NO	2	(60%)
NO OPINION (VOLUNTEERED)	3	(1%)

---

23. If you were a tenant in a building in which a known carrier of the AIDS virus were living would you (READ AND ROTATE)...?

MOVE OUT OF THE BUILDING	1	(13%)
CONTINUE TO SHARE COMMON FACILITIES SUCH AS LAUNDRY	2	(43%)
CONTINUE TO LIVE IN THIS BUILDING BUT NOT SHARE FACILITIES	3	(41%)
NO OPINION (VOLUNTEERED)	4	(3%)

---

24. What do you think are the main ways that someone could catch the AIDS virus? (PROBE...ACCEPT UP TO THREE RESPONSES)

SEX INTERCOURSE/CONTACT GENERAL	01	(76%)
HOMOSEXUAL TRANSMISSION	02	(7%)
DRUG/NEEDLES	03	(31%)
BODY FLUIDS	04	(16%)
BLOOD TRANSFUSIONS	05	(49%)
BLOOD CONTACT -- GENERAL	06	(14%)
CUTS/SCRATCHES/SORES	07	(10%)
URINE	08	(*)
SALIVA	09	(1%)
KISSING	10	(2%)
PROMISCUOUS SEX	11	(3%)
ANAL SEX	12	(1%)
SEX WITH AIDS CARRIER	13	(*)
SEXUAL CONTACT/BODY FLUIDS	14	(3%)
OTHER CASUAL CONTACT	15	(3%)
OTHER	16	(4%)
DON'T KNOW	17	(2%)
NO RESPONSE	18	(1%)

REFER TO APPENDIX C FOR COMPLETE VERBATIM RESPONSES

---

25. In your opinion, can a person who has the AIDS virus pass it on, even though he or she has no symptoms of illness from the virus?

YES	1	(76%)
NO	2	(7%)
NOT SURE/DON'T KNOW (VOLUNTEERED)	3	(16%)

26. Do you think that AIDS will influence the way in which you live your life to any great extent?

YES	1	(36%)
NO	2	(64%)
NO OPINION (VOLUNTEERED)	3	(*)

Now I have a few questions about how AIDS is transmitted. Again, while some of these may be sensitive to you, it is important that we get your opinion. In your view can a person become infected with the AIDS virus by...(READ AND ROTATE Q27 THROUGH Q32)?

27. Donating blood.

YES	1	(47%)
NO	2	(52%)
NO OPINION (VOLUNTEERED)	3	(1%)

28. Eating food prepared by someone who is infected with the AIDS virus.

YES	1	(22%)
NO	2	(74%)
NO OPINION (VOLUNTEERED)	3	(4%)

29. Sharing office equipment with a co-worker who is infected with the AIDS virus.

YES	1	(12%)
NO	2	(85%)
NO OPINION (VOLUNTEERED)	3	(3%)

30. Children playing with another child who is infected with the AIDS virus.

YES	1	(29%)
NO	2	(67%)
NO OPINION (VOLUNTEERED)	3	(3%)

31. A man having sex with a woman who is infected with the AIDS virus.

YES	1	(98%)
NO	2	(1%)
NO OPINION (VOLUNTEERED)	3	(1%)

32. A woman having sex with a man who is infected with the AIDS virus.

YES	1	(99%)
NO	2	(1%)
NO OPINION (VOLUNTEERED)	3	(1%)

END OF ROTATION

---

33. What do you think is the most important precaution that people can take to prevent the spread of AIDS? (PROBE...ACCEPT UP TO THREE RESPONSES)

CONDOMS	01	(49%)
CELIBACY/ABSTINENCE	02	(19%)
DON'T SHARE NEEDLES	03	(15%)
TRANSFUSIONS	04	(10%)
AVOID AIDS CARRIERS	05	(4%)
QUARANTINE	06	(1%)
BE CAREFUL/SAFE SEX	07	(12%)
MONOGOMY/LIMITED PARTNERS	08	(23%)
KNOW YOUR PARTNER	09	(16%)
TESTING	10	(5%)
GOOD/MORAL LIFE-STYLE	11	(4%)
MEDICAL/LAB PRECAUTIONS	12	(3%)
EDUCATION	13	(9%)
CAUTION CUTS/WOUNDS	14	(1%)
AVOID KISSING	15	(1%)
KEEP CLEAN	16	(2%)
IDENTIFY CARRIERS	17	(1%)
OTHER	18	(7%)
DON'T KNOW	19	(5%)
NO RESPONSE	20	(1%)

REFER TO APPENDIX C FOR COMPLETE VERBATIM RESPONSES

I'm going to read you a list of possible ways of preventing the spread of the AIDS virus. For each one, I'd like you to tell me in your opinion how effective it is in preventing the spread of AIDS. Would you say (READ AND ROTATE Q34 THROUGH Q39)...is very effective, effective, somewhat effective or not effective at all?

34. Birth control pills.

NOT EFFECTIVE AT ALL..........1 (93%)
SOMEWHAT EFFECTIVE............2 (3%)
EFFECTIVE.....................3 (2%)
VERY EFFECTIVE................4 (1%)
NO OPINION (VOLUNTEERED)......5 (2%)

35. Condoms.

NOT EFFECTIVE AT ALL..........1 (4%)
SOMEWHAT EFFECTIVE............2 (30%)
EFFECTIVE.....................3 (36%)
VERY EFFECTIVE................4 (30%)
NO OPINION (VOLUNTEERED)......5 (1%)

36. Diaphrams.

NOT EFFECTIVE AT ALL..........1 (71%)
SOMEWHAT EFFECTIVE............2 (19%)
EFFECTIVE.....................3 (5%)
VERY EFFECTIVE................4 (2%)
NO OPINION (VOLUNTEERED)......5 (4%)

37. Washing after sexual relations.

NOT EFFECTIVE AT ALL..........1 (76%)
SOMEWHAT EFFECTIVE............2 (16%)
EFFECTIVE.....................3 (4%)
VERY EFFECTIVE................4 (3%)
NO OPINION (VOLUNTEERED)......5 (2%)

38. Not having sexual relations.

NOT EFFECTIVE AT ALL..........1 (4%)
SOMEWHAT EFFECTIVE............2 (3%)
EFFECTIVE.....................3 (15%)
VERY EFFECTIVE................4 (78%)
NO OPINION (VOLUNTEERED)......5 (*)

39. Having one partner in a long-term relationship.

NOT EFFECTIVE AT ALL	1	(4%)
SOMEWHAT EFFECTIVE	2	(9%)
EFFECTIVE	3	(27%)
VERY EFFECTIVE	4	(61%)
NO OPINION (VOLUNTEERED)	5	(*)

END OF ROTATION

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40. Do you strongly favour, somewhat favour, somewhat oppose or strongly oppose education programs in the schools to inform students about the way in which AIDS is spread and how to avoid becoming infected?

STRONGLY OPPOSE (SKIP TO Q43)	1*	(1%)
SOMEWHAT OPPOSE (SKIP TO Q43)	2*	(1%)
SOMEWHAT FAVOUR (GO TO Q41)	3	(7%)
STRONGLY FAVOUR (GO TO Q41)	4	(92%)
NO OPINION (VOLUNTEERED)	5	(*)

IF "STRONGLY FAVOUR, OR SOMEWHAT FAVOUR" TO Q40, ASK:

41. Do you think that school education programs to inform students about the spread of AIDS should be mandatory?

YES (GO TO Q42)	1	(90%)
NO (SKIP TO Q43)	2*	(10%)
NO OPINION (VOLUNTEERED)	3	(*)

IF "YES" TO Q41, ASK:

42. At what grade do you think these programs should begin?

PRIMARY/KINDERGARTEN	1	(5%)
ONE TO SIX - ELEMENTARY	2	(40%)
SEVEN TO NINE - JUNIOR HIGH SCHOOL	3	(52%)
TEN TO TWELVE - HIGH SCHOOL	4	(2%)
NO OPINION (VOLUNTEERED)	5	(*)

43. Now, we would like to know who you think should have the main responsibility for informing people about preventing the spread of AIDS? (READ AND ROTATE LIST...ACCEPT ONLY ONE RESPONSE)

PROVINCIAL HEALTH DEPARTMENT	01	(22%)
AIDS ORGANIZATIONS	02	(7%)
DOCTORS	03	(16%)
FEDERAL HEALTH DEPARTMENT	04	(45%)
ALL OF THEM (VOLUNTEERED)	05	(6%)
GOVERNMENT GENERAL (VOLUNTEERED)	06	(2%)
THE FAMILY (VOLUNTEERED)	07	(1%)
NO OPINION (VOLUNTEERED)	08	(2%)

Would you send your child to school with confidence, misgivings or not send the child at all if...(READ AND ROTATE Q44 THROUGH Q49 IF VOLUNTEERS "NO CHILDREN" STATE, "Well, if you did have children..." AND REPEAT QUESTION)

44. the teacher was a man who was exposed to the AIDS virus?

NOT SEND THE CHILD AT ALL	1	(23%)
MISGIVINGS	2	(36%)
CONFIDENCE	3	(38%)
NO OPINION (VOLUNTEERED)	4	(3%)

---

45. the teacher was a woman who was exposed to the AIDS virus?

NOT SEND THE CHILD AT ALL	1	(23%)
MISGIVINGS	2	(35%)
CONFIDENCE	3	(39%)
NO OPINION (VOLUNTEERED)	4	(3%)

---

46. the teacher was a homosexual who was exposed to the AIDS virus?

NOT SEND THE CHILD AT ALL	1	(29%)
MISGIVINGS	2	(37%)
CONFIDENCE	3	(31%)
NO OPINION (VOLUNTEERED)	4	(4%)

---

47. another student has been exposed to the AIDS virus?

NOT SEND THE CHILD AT ALL	1	(16%)
MISGIVINGS	2	(43%)
CONFIDENCE	3	(38%)
NO OPINION (VOLUNTEERED)	4	(4%)

48. another student has been exposed to the AIDS virus through blood transfusion?

NOT SEND THE CHILD AT ALL.....1 (15%)
MISGIVINGS....................2 (41%)
CONFIDENCE....................3 (40%)
NO OPINION (VOLUNTEERED)......4 (4%)

---

49. another student has been exposed to the AIDS virus through sexual activities?

NOT SEND THE CHILD AT ALL.....1 (21%)
MISGIVINGS....................2 (45%)
CONFIDENCE....................3 (30%)
NO OPINION (VOLUNTEERED)......4 (4%)

END OF ROTATION

---

50. Medical experts have indicated that the AIDS virus cannot be transmitted by casual contact. How strongly do you believe the medical experts?

NOT VERY STRONGLY.............1 (19%)
NOT STRONGLY..................2 (11%)
STRONGLY......................3 (39%)
VERY STRONGLY.................4 (31%)

If your child was a carrier of the AIDS virus, would you...(READ AND ROTATE Q51 AND Q52)?

51. continue to send your child to school?

YES...........................1 (67%)
NO............................2 (29%)
NO OPINION (VOLUNTEERED)......3 (5%)

---

52. expect other parents to continue to send their children to the same school with your child?

YES...........................1 (59%)
NO............................2 (36%)
NO OPINION (VOLUNTEERED)......3 (5%)

END OF ROTATION

---

53. If you had casual contact with a known carrier of the AIDS virus, yet you knew that medical experts have indicated that the AIDS virus cannot be transmitted by casual contact, how concerned would you be that you might catch the AIDS virus?

NOT CONCERNED AT ALL	1	(23%)
NOT TOO CONCERNED	2	(26%)
SOMEWHAT CONCERNED	3	(30%)
VERY CONCERNED	4	(21%)
NO OPINION (VOLUNTEERED)	5	(1%)

---

54. Should testing for the AIDS virus be mandatory for everyone in Nova Scotia or should it be carried out on a voluntary basis only?

MANDATORY	1	(33%)
VOLUNTARY	2	(65%)
NO OPINION (VOLUNTEERED)	3	(2%)

---

55. Some people say that a person should be able to have a test for AIDS without anyone knowing the results.

Others say that the public has a right to know when any individual is tested positive for the AIDS virus.

And still others say that public health officials must be informed of the results of the test.

Which of these points of view most closely resembles your own?

WITHOUT ANYONE ELSE KNOWING THE RESULTS	1	(23%)
PUBLIC HAS THE RIGHT TO KNOW WHEN AN INDIVIDUAL TESTS POSITIVE	2	(18%)
PUBLIC HEALTH OFFICIALS MUST BE INFORMED OF THE RESULTS OF THE TEST	3	(59%)
NO OPINION (VOLUNTEERED)	4	(1%)

---

56. How confident are you that, if you tested positive for the AIDS virus, the results of the test would remain confidential?

NOT AT ALL CONFIDENT	1	(23%)
NOT TOO CONFIDENT	2	(35%)
SOMEWHAT CONFIDENT	3	(27%)
VERY CONFIDENT	4	(14%)
NO OPINION (VOLUNTEERED)	5	(1%)

---

57. Let us say that a physician carries out a blood test and finds a person has been infected with the AIDS virus. Do you think that the sexual partner(s) of the infected person should be traced and warned that they might have been exposed to the AIDS virus?

YES	1	(98%)
NO	2	(2%)
NO OPINION (VOLUNTEERED)	3	(*)

---

58. If sexual partners of carriers of the AIDS virus are to be traced, who should be responsible for tracing and informing the partners? (READ AND ROTATE...ACCEPT ONLY ONE RESPONSE)

THE AIDS CARRIER THEMSELVES	1	(24%)
DOCTORS	2	(18%)
DEPARTMENT OF HEALTH	3	(57%)
NO OPINION (VOLUNTEERED)	4	(1%)

---

59. Some people believe that in order to control the spread of a disease like AIDS, it would be beneficial to separate all AIDS carriers from the general population.

Other people believe that if other infection control procedures are followed, carriers of the AIDS virus can be part of the general population without being a threat.

Thinking about these two points of view, which position most accurately reflects your view?

SEPARATE AIDS VIRUS CARRIERS	1	(18%)
OTHER INFECTION CONTROL PROCEDURES	2	(81%)
NO OPINION (VOLUNTEERED)	3	(1%)

---

60. Have you ever discussed AIDS and the spread of AIDS with your doctor, with your children or your parents? (ACCEPT MORE THAN ONE RESPONSE)

DOCTOR	1	(10%)
CHILDREN	2	(30%)
PARENTS	3	(19%)
NONE (VOLUNTEERED)	4	(54%)
NO OPINION (VOLUNTEERED)	5	(1%)

If taxpayers' dollars were to be spent on AIDS, there are a variety of areas to which funding might be directed.

In your opinion, how important would it be for government funds to be spent in the following areas. Would it be very important, somewhat important, not very important, or not important at all to spend funds on...(READ AND ROTATE Q61 THROUGH Q66)?

61. public education

NOT IMPORTANT AT ALL..........	1	(*)
NOT VERY IMPORTANT............	2	(2%)
SOMEWHAT IMPORTANT............	3	(11%)
VERY IMPORTANT................	4	(88%)
NO OPINION (VOLUNTEERED)......	5	(*)

---

62. home care services for AIDS patients

NOT IMPORTANT AT ALL..........	1	(2%)
NOT VERY IMPORTANT............	2	(7%)
SOMEWHAT IMPORTANT............	3	(39%)
VERY IMPORTANT................	4	(51%)
NO OPINION (VOLUNTEERED)......	5	(1%)

---

63. medical research

NOT IMPORTANT AT ALL..........	1	(1%)
NOT VERY IMPORTANT............	2	(*)
SOMEWHAT IMPORTANT............	3	(7%)
VERY IMPORTANT................	4	(92%)
NO OPINION (VOLUNTEERED)......	5	(*)

---

64. counselling for persons with the AIDS virus

NOT IMPORTANT AT ALL..........	1	(1%)
NOT VERY IMPORTANT............	2	(4%)
SOMEWHAT IMPORTANT............	3	(29%)
VERY IMPORTANT................	4	(66%)
NO OPINION (VOLUNTEERED)......	5	(1%)

---

65. testing facilities

NOT IMPORTANT AT ALL..........	1	(1%)
NOT VERY IMPORTANT............	2	(2%)
SOMEWHAT IMPORTANT............	3	(23%)
VERY IMPORTANT................	4	(74%)
NO OPINION (VOLUNTEERED)......	5	(1%)

---

66. a hospital for dying AIDS patients

NOT IMPORTANT AT ALL	1	(6%)
NOT VERY IMPORTANT	2	(11%)
SOMEWHAT IMPORTANT	3	(32%)
VERY IMPORTANT	4	(50%)
NO OPINION (VOLUNTEERED)	5	(1%)

END OF ROTATION

The next few questions are about the way AIDS is affecting sexual relations in society today.

67. Would you say the spread of the AIDS virus has changed your sexual habits a great deal, somewhat, not too much, or not at all?

NOT AT ALL	1	(70%)
NOT TOO MUCH	2	(8%)
SOMEWHAT	3	(11%)
A GREAT DEAL	4	(10%)
NOT APPLICABLE (VOLUNTEERED)	5	(2%)
NO OPINION (VOLUNTEERED)	6	(*)

Would you say that the existence of the AIDS virus has caused you to...(READ AND ROTATE Q68 THROUGH Q70)?

68. reduce the number of sexual partners

YES	1	(31%)
NO	2	(66%)
NO OPINION (VOLUNTEERED)	3	(3%)

---

69. become more cautious about whom to have sex with

YES	1	(48%)
NO	2	(49%)
NO OPINION (VOLUNTEERED)	3	(3%)

---

70. start using condoms as a precaution

YES	1	(30%)
NO	2	(67%)
NO OPINION (VOLUNTEERED)	3	(3%)

END OF ROTATION

71. Based on your current sexual habits, to what extent do you feel you are at risk of contracting the AIDS virus? Are you at great risk, some risk, little risk, or no risk at all?

NO RISK AT ALL	1	(75%)
LITTLE RISK	2	(18%)
SOME RISK	3	(5%)
GREAT RISK	4	(1%)
NOT WILLING TO ANSWER (VOLUNTEERED)	5	(1%)
NO OPINION (VOLUNTEERED)	6	(1%)

Now, I have a few final questions for statistical purposes...

72. What is your age, please?
(IF RESPONDENT REFUSES, OFFER TO READ CATEGORIES AND HAVE HIM/HER TELL YOU WHICH CATEGORY HE/SHE FALLS INTO)

18-19 YEARS	01	(5%)
20-24 YEARS	02	(9%)
25-29 YEARS	03	(12%)
30-34 YEARS	04	(13%)
35-39 YEARS	05	(15%)
40-44 YEARS	06	(11%)
45-49 YEARS	07	(8%)
50-54 YEARS	08	(6%)
55-59 YEARS	09	(7%)
60-64 YEARS	10	(5%)
65 YEARS OR OLDER	11	(10%)

---

73. What is your marital status?

SINGLE	1	(19%)
MARRIED	2	(68%)
COMMON LAW/CO-HABITATION	3	(5%)
DIVORCED/SEPARATED	4	(6%)
WIDOWED	5	(4%)

---

74. How many children under 18 are living in your household?

NONE	1	(49%)
ONE	2	(20%)
TWO	3	(21%)
THREE	4	(7%)
FOUR	5	(2%)
FIVE	6	(*)
MORE THAN FIVE	7	(*)

---

75. What is your religious affiliation? (DO NOT READ LIST...IF "PROTESTANT" ASK: Is that United, Anglican, Presbyterian Methodist, Pentecostal, Lutheran, Baptist, or something else than those?)

CATHOLIC	01	(36%)
UNITED	02	(19%)
ANGLICAN	03	(13%)
PRESBYTERIAN	04	(2%)
METHODIST	05	(*)
PENTECOSTAL	06	(1%)
LUTHERAN	07	(1%)
BAPTIST	08	(11%)
OTHER PROTESTANT	09	(6%)
JEWISH	10	(1%)
NO RELIGIOUS PREFERENCE/AGNOSTIC/ATHEIST (VOLUNTEERED)	11	(10%)
MUSLIM	12	(*)
HINDU	13	(*)
NO OPINION (VOLUNTEERED)	14	(1%)

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76. How often do you attend services at a church/synagogue/temple? (READ LIST)

NEVER	1	(13%)
SPECIAL OCCASION ONLY	2	(32%)
LESS THAN ONCE A MONTH	3	(8%)
ONE TO THREE TIMES PER MONTH	4	(14%)
ONCE A WEEK	5	(25%)
MORE THAN ONCE A WEEK	6	(6%)
REFUSE TO ANSWER (VOLUNTEERED)	7	(*)
NO OPINION (VOLUNTEERED)	8	(1%)

77.A Are you currently attending school, college, or university as a full time student?

YES (SKIP TO Q78)	6*	(7%)
NO (GO TO Q77.B)	A	

IF "NO" TO Q77.A, ASK:

77.B What is the highest level of schooling that you have completed?

PUBLIC/ELEMENTARY SCHOOL (GRADE 1-8)	1	(8%)
SOME HIGH SCHOOL	2	(28%)
GRADUATED HIGH SCHOOL (GRADE 12 OR 13)	3	(25%)
VOCATIONAL/TECHNICAL/COLLEGE/CEGEP	4	(15%)
SOME UNIVERSITY	5	(4%)
GRADUATED UNIVERSITY	7	(13%)

78. Are you currently employed outside the home?

YES	1	(61%)
NO	2	(39%)

---

79. What is your occupation, that is what are your main job responsibilities? (PROBE: What type of company do you work for? ANSWER MUST BE AT LEAST TEN WORDS)

PROFESSIONAL	01	(4%)
AGRICULTURAL	02	(4%)
CIVIL SERVANT	03	(2%)
OWNER/SELF-EMPLOYED	04	(6%)
MANAGEMENT/EXECUTIVE	05	(6%)
CULTURAL	06	(1%)
TEACHER	07	(5%)
MEDIUM-LEVEL SERVICE	08	(9%)
LOW-LEVEL SERVICES	09	(14%)
MED-LEVEL OFFICE WORKER	10	(5%)
LOW-LEVEL OFFICE WORKER	11	(7%)
MED-LEVEL PRODUCTION WORKER	12	(14%)
LOW-LEVEL PRODUCTION WORKER	13	(8%)
HOUSEWIFE	14	(5%)
STUDENT	15	(1%)
RETIRED	16	(5%)
ARMY	17	(2%)
UNEMPLOYED	18	(1%)
SCIENTIFIC/TECHNICAL	19	(2%)

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80. Which of the following income groups includes your annual household income? (READ CHOICES)

LESS THAN $ 5,000	01	(3%)
$ 5,000 - $ 9,999	02	(8%)
$10,000 - $14,999	03	(11%)
$15,000 - $19,999	04	(13%)
$20,000 - $24,999	05	(12%)
$25,000 - $29,999	06	(13%)
$30,000 - $34,999	07	(8%)
$35,000 - $39,999	08	(7%)
$40,000 - $44,999	09	(5%)
$45,000 - $49,999	10	(4%)
$50,000 AND OVER	11	(17%)

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81. Sex. (BY OBSERVATION)

MALE	1	(50%)
FEMALE	2	(50%)

C. VERBATIM RESPONSES

Question 2

I'd like to get your opinion about one health issue. Over the last few years, there has been a lot of discussion about the disease known as AIDS. In your opinion, what would be the best way of describing the disease known as AIDS?

01. Deadly/Fatal -- It is a deadly disease. / Disease which will kill anyone who gets it. / Deadly to 100% of those who get it. / Fatal, terminal. / It kills people. / Deadly virus sort of thing -- I read stories in books. / Deadly. / Deadly killer without a cure. / Deadly disease. / It kills people. / It's terminal -- 95% chance of death. / Deadly -- can't cure it. / Fatal. / Kills people. / Deadly -- there are no cures. / It's a killing disease. / Very deadly -- it kills you. / It is fatal. If you contact AIDS, you die. / Threatens the victim's life. If you get it, there is no cure. / It's very dangerous. If you catch it, you die. / Death -- there is no cure for it. / Deadly disease. / The disease is almost always fatal. / It's a killer. / Fatal once you have been infected. / Fatal. / Kills you. / Fatal and incurable. / Deadly, if you get it you won't survive.

02. Incurable -- Incurable -- it cannot be cured. / It is an incurable disease. / Incurable so far -- if you got it, there is nothing you can do about it. / No cure. / Let's just say unforgiving. / A disease without a cure. / It's scary -- the fact that there is no cure. / It is an incurable disease. / You can't do anything for people. / No cures. / Incurable. / It is an incurable, sexually transmitted disease. / It's a disease -- once you get it, you don't get rid of it.

03. Attacks Immune System -- The breakdown of the immune system. / Immune deficiency syndrome. / AIDS breaks down the immune system -- it's easy to get sick. / It is as it says -- immune deficiency. / It's an immune deficiency disease. / It's a disease that ruins the immune system that makes you susceptible to any disease going. / Breaks down immune system. / A break down of the immunity system. / Immune deficiency syndrome -- body can't fight disease. / Breaks down immunities. / Breaks down immune system -- any virus can kill you then. / Immune deficiency type of disease that attacks your immune system. / No immunity to anything. / It's a shut down of your immune system -- has all its complications which is the fatal end of it. / A break down of the immune system. / It is disease of the immune system. / It has a lot to do with the food and drugs -- it hurts the immune system. / Breaks down immune system. / A disease that attacks the immune system. / Attacks your immune system. / It destroys the immune system -- you catch the common cold and die. / A condition that destroys our immune system -- this disallows us from fighting off other diseases. / Immune deficiency -- disease that affects the immune system. / It attacks the immune system. / A breakdown of the

immune system. / Slowly kills the person -- breaks down the immune system -- a cold can kill you. / Caused by HIV, destroys immune system. / Breakdown of the immune system -- people contract other diseases and can't fight them off. / Immune deficiency breakdown. / AIDS is AIDS -- it's an immune deficiency -- it's a disease like any other disease. / It destroys the body's immune system. / Breaks your immune system down and you eventually die from it. / Acquired Immune Deficiency Syndrome.

04. Contagious/Communicable -- It is a communicable disease. / Contagious. / Communicable and deadly. / Contagious -- a high rate of spreading. / It is highly contagious. / Highly contagious.

05. Sexually Transmitted -- Sex. / Contacted through sexual relations. / Contacted through sexual activity -- men and women alike. / Sexually transmitted -- passed by internal fluids. / Sexual disease. / Contracted through sexual intercourse or blood transfusions and the use of contaminated needles. / Sexually transmitted disease. / Because of multiple sex partners. / Worse than syphillis or gonorrhea. / Veneral disease. / A very dreadful disease -- contracted by having sex. / Passed by sexual relations. / Sexual contact transmitted. / Transmitted sexually through transfusions. / Have to be cautious who you sleep with because no one knows how you get it. / Transmitted by not taking precautions and having multiple sexual partners. / Sexual disease. / Sexual communicable diseases of epidemic proportions. / Sexual disease. / Having intercourse. / Having sex -- two males or two females. / If you keep away from sex you probably won't get it. / Sexual transmission -- it is passed through body liquids. / It is sexually transmitted. / You get it through intercourse. / Sexually transmitted -- drug abuse and blood transfusions. / Picked up by people from carriers through sex. / Sexually transmitted disease. / It's a sexually transmitted disease that can have extreme consequences. / It is transmitted sexually. / Sexually contracted disease. / It's transmitted through sexual contact. / Sexual intercourse -- someone has the virus, has sex, transmits, and goes on. / Mainly transmitted through sexual activities that allows the virus in the sperm of males to enter the bloodstream of that male's sexual partners. / Get it through sex -- passing of bodily fluids. / Sexually transmitted disease that attacks your immune system.

06. Homosexually Transmitted -- Homosexually transmitted. / Homosexuals and drug users are high risk groups. / Spread by gays and their unhuman ways. / Homosexually transmitted disease. / Disease of gays. / Homosexual disease. / Transmitted through gays.

07. Drug Use -- Drug use. / Needles -- dope -- a dirty needle -- I don't know what needles have to do with AIDS. I just heard it had something to do with it. / Also something to do with those who use drugs.

08. A Virus -- Virus. / A virus -- it's like a plague from the past that's

deadly. / Infectious virus. / It's like a plague -- only it's a virus. / It appears to be a disease transmitted by a virus into the blood stream.

09. Blood Transfusions -- Contracted by blood transfusions. / Get it through blood transfusions if needles are dirty. / Giving blood can be dangerous -- can get in blood and be passed to you. / Passed by blood transfusions or homosexual activity or hetersexual sex.

10. Blood Disease -- Blood disease. / Passed through blood -- if AIDS blood is on cut of someone else they could catch it. / Blood disorder.

11. Sinful/Unnatural -- Punishment for unnatural acts and sexual freedom. / Get it through off sexual relations, mostly people don't know very much about it. / Brought on by actions which are abnormal -- men sexually interacting with each other. / It is a sin.

12. Other Methods of Transfusions -- Heard that AIDS is a disease that one can catch through mouth contact and stuff. / You get it also from public places. / People say you can get it through cuts or spit. I don't now it that's true. / Passed also through saliva -- one to another.

13. Dangerous/Hazardous -- A very dangerous disease that I wouldn't want to come in contact with. / Dangerous. / Something to avoid -- that's what it is. / Hazardous to your health. / It's dangerous and is spreading.

14. Like Cancer -- It's more painful than cancer. / It is like cancer. / Cancerous disease -- it kills slowly like cancer. / A form of cancer -- the way it attacks the body immune system.

15. Terrible/Frightening -- Frightening. / Awful. / Bad. / Dreadful. / I am scared that it may affect my own family. / Horrible -- don't think I've really felt the impact yet. / Scary. / It's a sad thing -- terrible and more people getting it. / It's an awful, terrible disease. / Scary because no one really understands it. / A dreadful disease.

16. Social Disease -- Social disease. / It's a social disease.

17. Epidemic -- Epidemic like. / Could relate to the black plague -- nothing I can think of right now. / Epidemic -- there are so many people who die with it now.

18. Destroys the Body -- It is like a raging uncontrolled fire in your body destroying everything. / Deterioration of the body. / Something that slowly eats away at your body until you die.

19. Knowledge/Awareness -- Awareness of people. / There is not a lot known about it.

20. Disease -- It's an illness. / Disease.

21. Carriers May Not Show Symptoms -- You could have it for years before signs show up. / Can be a carrier and not suffer any Effects.

22. Other -- Syndrome. / If the host is in very good health, it will be very difficult for the virus. / It's disease that came from nowhere. / It affects the nervous system. / Overpublicized -- we know no one with it. / Pretty brutal -- I'm not prepared to answer these questions, it's pretty much a drag -- takes a lot of costs and changes people's life-styles. / People have to be careful what they're doing. / Not very widely spread in Nova Scotia as compared to cancer. / It's a disease that strikes down anyone. / Concerns all of us. / It seems to be an increasing problem today, that's all. / It's awful because it tends to take younger people in their prime. / It creates a lot of suffering. / AIDS -- what it stands for. / People who have it should be isolated.

23. Don't Know

24. No Response

Question 10

Which group of people do you think is most likely to catch the AIDS virus?

01. Homosexuals -- Homosexuals -- I'm just going by what I've heard about them. / Homosexuals it was first found in -- they are still the number one danger but we are all at risk. / Homosexuals are said to be -- appeared in their community before anyone. / Homosexuals, it's spread by them. / Homosexuals or a woman who goes with a homosexual. / Homosexuals. / The ones we've heard a lot about; namely, homosexuals. / Homosexuals are at high risk -- it's quite prevalent in the gay community. / It is their business but they should be more careful. / It is most prevalent of the gay community over the others. / Homosexuals and those closely associated with them and people with many partners. / Homosexuals -- are quite high risk -- it was brought around by them and they are in most danger. / Homosexuals are said to be at high risk -- but really, whoever is going to get it is going to get it -- we are all at risk. / From what I've read and heard, homosexuals seem most likely. / Homosexuals from what we seem to hear, seems to be the most likely. / Homosexuals -- just what I heard from the media. / Gay fellows are at risk -- they are most susceptible to it. / Homosexuals and drug users and Haitians, homosexuals. / Gays. / There are three groups: the ones at high risk are homosexuals first, drug users second and hemophiliacs. / Gays -- just that. / It applies only to those groups -- homosexuals. / It appears to be homosexuals. / Homosexuals and habitual drug users. / From information gained, it would appear that homosexuals are at a greater risk. / Homosexuals -- high risk -- found that they had it first. / Homosexuals and drug abusers drug abusers I guess. / Homosexuals -- people who get blood transfusions, sexually active people. / Gays -- males most likely. / Homosexuals, heterosexuals, hemophiliacs and certain cultural groups i.e., East Indians. / Homosexual men. / Homosexuals -- it's not that they're more susceptible -- it's because of the circumstances that create a greater risk. / Homosexuals and it's spreading. / Male homosexuals up to now, but this thing is a process and it is changing such that all people are becoming more likely to contact the disease. / Gay population. / From those who have homosexual contact. / Gays. / Gay group -- anyone can catch it, but they're more apt to get it. / Homosexual problem -- predominate in the life-styles they live. / Gays and people who run around. / Homosexuals -- high risk group -- they had it first. / Homosexuals and lesbians -- this is where it started and now it's catching on. / Homosexuals -- they are very, or have many sexual partners -- their methods make them more at risk of getting AIDS. / Homos and I think people who share needles for drug abuse. / It was in the homosexual community but it's now spreading. / Gays and people from Haiti -- that's what I heard from the news. / Homosexuals living that life-style are at higher risk because they tend to have a large number of sexual contacts. / Homosexuals -- this is what the news is mainly about -- just going by what I heard about the deaths that have occurred from AIDS. / Homosexuals -- because they carry the disease.

02. Sexually Active/Promiscuous -- People who are sexually active with many partners. / People who run around -- prostitutes. / The group that travels and is sexually active. / The people with different partners all

the time, in a sexual way. / Sexually promiscuous people and drug abusers. / Promiscuous people who don't use proper protection. / People who are too flirtatious. / Promiscuous young people -- they run around and don't know very much. Some of them that is. / Promiscuous people -- people who have many sexual partners. / Promiscuous people who don't stay with just one person. / Overactive people when it comes to their sex lives. / People with multiple sex partners.

03. Drug Users -- Drug users and homosexuals -- it depends on their life, homosexuals I guess. / Needle users -- unclean needles used for instance, drugs. / People who take drugs through contaminated needles. / Drugs and homosexuals. / Drug users who share needles. / Drug users -- needles being used by different people -- no sterilization. / People involved with drugs and who use needles.

04. Young People -- Young people -- must watch who they go out with to stay at low risk. / Young people -- except those taking needles. / Young people not married and having an active sex life with many partners. / Young people -- high risk, you know, sex. / Teenagers because they are more sexually active. / Younger people in their 20s and 30s. / The young people are at the age that they are not worried about anything: drugs, homosexuality or sex. / Teenagers because they are more sexually active than older people. / Young, wild people going to dances -- they don't know too much about it and they might get it. / Young people because they are so innocent -- they are not aware of the seriousness of AIDS. / The younger generation. / Girls that are in their early twenties because of how they behave sexually.

05. Street People -- People who walk the streets and sleep with anyone and not really clean about themselves. / Those who are out on the street and sleeping around.

06. Immoral/Out for a Good Time -- Immoral people -- people not living up to the right principles of living. / All the people with pornographic habits like lesbians and homosexuals -- also hemophiliacs are also at high risk. / Individuals not in normal family situation and who ask for it -- people who go out and take risks. / People who go out to parties and lounges -- meet someone in a bar with AIDS. / People out just looking for a good time.

07. Hemophiliacs -- Hemophiliacs through blood transfusions.

08. Anyone -- Anyone can get it -- I do not believe there is any group at the moment. / Both gay and heterosexual people are at risk -- more the heterosexuals than gays because of the fear by the gays.

09. Other

10. Don't Know

11. No Response

Question 24

What do you think are the main ways that someone could catch the AIDS virus?

01. Sexual Intercourse/Contact General -- Sexual intercourse. / Through intercourse. / Intercourse. / Through contact and intimate contact. / Sexual contact. / Sex. / Sexual relations. / Sexual activity. / Sex -- normal way. / Sexually transmitted. / Sexual disease -- contracted sexually. / Through sexual intercourse. / Sex -- homosexuals and heterosexuals have sex -- they can catch it. / Through sex -- having sex is a really good way of getting it. / Sex contact -- that's it. / Through intercourse. / Through sex. / Sexually transmitted disease. / Physical contact -- sexual contacts. / Sexual contact -- well it is a sexually transmitted disease. / Direct sexual transmission. / The sexual contact. / Sexual intercourse -- having sex is dangerous stuff. / Sexually transmitted -- intercourse and oral sex. / Sexual intercourse -- that's it -- no main ways. / Through sex -- that's how it all started -- the easiest way to get it -- no other way. / Through intimate sexual contact. / Sexual activity for sure, mostly homosexuals. / Intercourse -- someone has sex, transmits, has sex with another and so. No other way.

02. Homosexual Transmission -- Homosexual acts. / Through homosexuality. / Sexual activity -- homosexual activity. / Homosexual contact. / Being a member of high risk group like homosexuals and intravenous drug users. / Homosexuality. / Homosexuals. / Homosexuals who have intercourse with a lot of partners. / Same as I mentioned earlier -- homosexual activity -- any sexual activity really. / Homosexual activities.

03. Drugs/Needles -- Unsterilized needles used by drug users. / Dope addicts using contaminated needles. / Drug abusers. / Using dirty needles for drugs. / Needles. / Needles -- drug abuse. / Sharing a needle for drug abuse. / Needles, don't share. / Sharing needles. / Shared needles -- drug abuse -- blood to blood, basically blood transfusions -- that's understood -- well, I guess it's not -- blood to blood with infected material. / With the use of needles and drugs -- common use of one needles by several people. / The dirty needle bit with drugs. / Drug needles. / Using someone else needle. / Through infected needles -- someone using drugs by needles. / Sharing needles for drugs -- can't think of any at the moment. / Contaminated needles. / Infected needles from drug users -- infected blood. / Unclean and unsterile needles you hear stories about people who use drugs needles -- whatever. / Needles -- personally injected -- two or three using same needle. / Dirty needles -- someone reusing a needle that carries the virus. / Using needles. / Improper sharing of needles. / Sharing needles. / Drug users -- sharing dirty needles. / Needles. / Needles used for drugs. / Bad needles. / Drug users use needles could be infected from someone else. / Through drug needles. / Intravenous drug users. / Using needles after someone else. / Users of drugs through needles -- if they're dirty they're dangerous. / Contaminated needles. / Sharing needles. / Dirty needles are bad, passing them around is bad. / Drugs that use needles. / Druggies -- dirty needles being passed around to lots of people. / Intravenous drug use and born with AIDS.

04. Body Fluids --- Body fluids. / Bodily fluids -- only blood and you know, not through. / Body fluid exchange. / Bodily fluid involving contact. / Bodily fluids. / Semen to blood. / Exchange of bodily fluids. / Body fluids -- secretion. / Transmission of bodily fluids. / Body fluid.

05. Blood Transfusions -- Blood transfusions again, must watch for dirty needles. / Through blood transfusions. / Blood transfusions -- if I had AIDS, gave blood, and someone else got my blood they would get AIDS. / Blood transfusions. / Blood transfusions from mother to child -- if she has the virus. / Blood -- infections and transfusions. / Blood transfusions -- if AIDS blood is passed to someone else, they can get it. / Blood transfusions -- someone who needed blood may get AIDS victim's blood. / Infected blood -- transfusions might do it. / Blood transfusions -- dirty needles are not good. / Slight chance through blood transfusions. / Contaminated blood transfusions yes, but not much of a problem anymore. / Transfusion of blood. / Blood transfusions -- AIDS blood passed on through to good blood. / Some kinds of blood transfusions. / Blood -- blood could be infected then you can get it if you take the blood. / Blood transfusions -- needles not sterilized may contain AIDS. / Blood transfusions -- giving blood is dangerous -- dirty equipment used a lot. / Blood donors. / Transmission of blood, but only through doctors.

06. Blood Contact -- General -- Blood to blood contact. / By exposure to infected blood. / Blood mixed with your own that has the virus. / Contact with blood of a person carrying AIDS. / Blood contact -- someone with the AIDS virus-- blood touching blood. / Blood contact. / Infected blood. / Blood. / Pretty well any way blood can be transmitted. / Through blood contact. / Contact with blood -- very particular contact with blood. / Transfer of blood and body fluids. / Through the exchange of blood from one person to another. / Blood to blood. / Through blood. / Also, blood-related transmission. / Handling blood. / Blood. / Through blood and other body fluids.

07. Cuts/Scratches/Sores -- Through a cut. / Blood -- a person with AIDS has an open cut and it goes to another person. / Through cuts on body -- can pass bad blood to good blood like that. / Blood -- if you get a cut. / Cuts. / Scratches on skin. / Passing of blood by way of cuts on open wounds. / Infected because of an open cut -- cut on hand and you shake hands with a carrier. / Working with AIDS -- blood with a cut. / Then incidental things -- open sores, suppose you're conducting first aid to a carrier and you have a cut in your finger. / A dentist in his office with someone's teeth and he has a cut on his hand anyone with open wounds. / Has to get into the blood stream i.e., by an open cut or wound. / Open cut -- if youre around a carrier with an open cut. / Personal contact watch out for cuts and passing of blood. / Open sores. / Infected blood -- it's another way -- received infected blood -- if you cut your finger and exchange of body fluids -- any kind of exchange. / Cuts can pass bad blood to good blood. / A cut and come in contact with blood. / Through blood -- like cuts and accidents.

08. Urine -- Possibly carried through urine. / Urine.

09. Saliva -- Saliva. / Spit. / Spitting -- case in the States, man arrested for attempted murder.

10. Kissing --- Kissing. / Breathing mouth contact. / Kissing.

11. Promiscuous Sex -- Sex -- got to watch who you see -- find out if they are AIDS carriers. / Sexual contact without protection. / Sleeping around. / Having a lot of sexual partners.

12. Anal Sex -- Sexual contact of specific kinds -- like anal intercourse. / Improper sexual behaviour -- shouldn't engage in rectal intercourse without proper protection, condoms and cleanliness.

13. Sex with AIDS Carrier -- Sexual contact with carrier. / Sexual contact with someone infected.

14. Sexual Contact and Bodily Fluids -- Sexual contact -- if body fluids mix, you can get it if one has it. / Being sexually active -- exchanging seminal or bodily fluids. / Sexual contact -- body fluids have AIDS in them -- that's a good way to get it. / Sexually -- again, the passing of body fluids. / Sexual transmission -- through passing of body fluids -- sex. / Intercourse -- when body liquids pass, AIDS can be passed. / Sexual contact -- passed by body fluid. / Sexual transmission passing of body fluids. / Sexual intercourse body liquids passed. / Sexual activities -- passing of body fluids from AIDS victim.

15. Other Casual Contact -- Even eating and doing dishes. / Eating or drinking after anyone who has the AIDS virus. / Using toothbrushes from victims. / Using their razors. / Shaking hands.

16. Other -- Dirt -- not keeping your body clean. / Very close contact. / Bathrooms. / A mother can pass it on to her unborn child.

17. Don't Know

18. No Response

Question 33

What do you think is the most important precaution that people can take to prevent the spread of AIDS?

01. Condoms -- Condoms. / Condoms are good -- they stop body fluids. / Condoms are good -- stop body fluids from entering woman. / Use condoms if you have sex with different partners. / Use of prophylactics. / Use of condoms. / Use condoms. / Use of condoms during intercourse. / Protecting yourself before you have sex -- using condoms -- they're good. / The use of condoms for sex. / Condoms stop semen and prevent the man from getting it. / Condoms -- if it is passed by body fluids, condoms would do the trick. / Condoms are good -- stops fluids. / Protect themselves using condoms. / Safe sex -- the use of condoms. / If you've got to get around on the town, use condoms. / If you are going to have sex, use a condom. / Should use protection such as a condom. / Using condoms stops bodily fluids -- that's good. / Safe sex -- condoms. / Well, of you're not interested in knowing your partner, then condoms. / For homosexuals and heterosexuals use condoms. / Take medical precautions -- use condoms. / Using proper contraceptive methods. / Use of contraceptive by the male. / In the gay world, take precautions to use condoms. / Contraceptives -- it's a joke though -- condoms work. / Safe sex -- condoms and knowing your partner. / If engaging in sex, then use condoms and cleanliness. / Use a rubber. / Use protective condoms. / Condoms -- stops passing of bodily fluids. / If they're having sex, use condoms. / Condom use.

02. Celibacy/Abstinence -- Stay away from having sex -- you could be at risk. / Not having sex is pretty good too -- very low chance of getting AIDS. / Stay away from sex -- you wouldn't have too much chance of getting it then. / Stop having sex. / Abstinence. / Total abstinence. / No sexual contact. / No sex. / Celibacy. / Not have sex. / No sexual relations. / No relationships. / Abstain from sex. / Stop completely having sex. / No sexual activity. / If in doubt -- don't. / Celibacy. / No sex for people of they have AIDS. / Not being sexually involved. / Not having sex would be effective, but no one should stop living. / Not having sex at all. / No sexual contact. / Abstinence. / No sexual relationships. / Don't have sex. / Staying away from sex. / No sex at all. / Stay away from sex. / Stop having sex. / Avoiding contact. / Stay at home, ha! ha! -- don't have any sex, stay at low risk. /

03. Don't Share Needles -- Don't use other people's needles. / Don't use needles other people use -- they may have AIDS. / If a drug user, use your own needles, and don't share them. / Intravenous drug users -- not sharing needles. / Use clean needles. / Lessen drug use. / Drugs and staying away from sharing needles. / Filthy needles might have AIDS on them -- shouldn't use them. / Needles. / Don't share needles. / Don't use needles. / Do not share needles. / Don't use other people's needles -- can't do much about blood donations. / Stay away from illegal drugs. /

Don't share needles I guess and things like that. / Not to abuse intravenous drugs. / Stop using intravenous drugs. / Through needles, could have contaminated needles that someone else had used. / Do not share needles. / Don't reuse needles -- I guess that's it.

04. Transfusions -- Blood transfusions. / Not have blood transfusions unless you are sure the blood is clean of the AIDS virus. / Avoid blood transfusions or using other people's needles. / Not giving blood. / Keeping away from contaminated blood. / Giving blood can be dangerous -- passing of bad to good blood. / A lot of things like blood transfusions are out of a person's control. / If need blood transfusion, make sure it is screened. / Screen blood transfusions. / Have blood screened through transfusions. / Blood screening. / Make sure all blood is okay.

05. Avoid AIDS Carriers -- No contact with person with AIDS virus. / Stay away from people who have AIDS. / Stay away from others who have it.

06. Quarantine -- If someone has AIDS they should be quarantined. / Being under quarantine -- locking them all away. / Isolate them -- but that isn't right.

07. Be Careful/Safe Sex -- Use protections available. / They must be very careful in their sexual relations. / Be careful how they have sex. / The use of protection during intercourse. / Careful sex. / Use a little discrimination and common sense in sexual activities. / Safe sex. / Watching yourself -- taking precautions -- condoms if having casual sex. / Careful in controlling sexual endeavours. / Use protection. / Safe sex is one way -- no -- mainly check partners. / Precaution before sexual intercourse. / Practice safe sex. / You have to be careful of what you do.

08. Monogomy/Limited Partners -- Monogamy. / One partner only. / Restrict sex. / Staying home with the wife or the wife staying home with the husband. / Having one partner. / One long-term partner. / Being faithful to your partner. / Stick to one partner. / Not have too many sexual partners. / Promiscuous sex. / One sex partner for life. / Cutting back on partners. / A monogamous relationship. / Sexual intercourse with more than one partner before marriage. / Find partner without it and stick with one partner. / Refraining from several partners. / Refrain from promiscuity. / Having one partner. / Staying with your one mate. / Monogamous. / Monogamy. / Not having premarital sex. / Not having a lot of sexual partners. / Fidelity. / Not having sex unless you are married. / One partner who doesn't have AIDS also stay at low risk. / Restricting sexual activity. / Limiting your casual sex -- put yourself at low risk. / Stop being promiscuous. / Limited number of partners -- sexual partners. / Control sexual promiscuity in general. / Limiting sexual partners.

09. Know Your Partner -- Know who you're having sex with. / Being careful with who you go out with. / Be choosey in choice of sex partners. / Watch what sexual partners you have. / Don't have a wild sex life -- know your partners -- be aware of it. / Watch sexual partners. / Be careful about sexual partners. / Being careful who you choose as a partner. / Pick and choose their partners. / Be sure about partners you're with -- who they've been with. / I guess it would be to control the company you keep. / Knowing your partner. / Check your partner. / Know your partner. / Know your partner -- a monogamous relationship is best. / Knowing sexual history of your partner. / Know your partner. / Be careful with who you have sex. / Know that person well. / Watch who you go out with -- check out your date -- see if they're clean. / Confrontation to potential partners. / Sexual life-style -- depends on person you are sleeping with and how many. / Knowing their partners or being sure of them anyway. / Discuss the problem before having sex. / Be careful who you go out with -- make sure they don't have AIDS. / Don't go running around -- watch who you sleep with. / Stay home -- got to be careful these day -- watch who you go out with. / Be careful who you sleep with.

10. Testing -- Ask if they could get tested. / Blood tests. / Test before marriage. / You and your partner should be tested for AIDS. / Get check-ups often. / Check yourself. / If someone is in doubt, get tested before you sleep with people.

11. Good/Moral Life-Style -- Lead a good life. / Setting a good standard of living for yourself. / If morally weak try to avoid one situation. / Living a moral life-style. / Life-style changes. / Not committing fornication or adultery.

12. Medical/Lab Precautions -- If medical -- use safety procedures. / Using sterile gloves while working in a lab. / By wearing gloves when working with blood, etc.

13. Education -- Have more teaching and testing. / Get the most information they can on AIDS. / Awareness -- various governments must make us aware of it. / Education on AIDS. / Learn about it. / Education and learning. Keeping up to date with current studies.

14. Caution With Cuts/Wounds -- Keep cuts bandaged. / Careful around open wounds and so on. / If you have cuts on your body, then don't partake in sex.

15. Avoid Kissing -- Avoid kissing. / Stop kissing. / Don't kiss people with sores.

16. Keep Clean -- Keep everything sanitary and clean. / Keeping clean and taking care of health.

17. Identify Carriers -- If positive with the AIDS virus tell others before having sex. / Getting carriers names out into the open.

18. Other -- Nothing is safe -- they say condoms are, but nothing really is. If you're going to get it, you get it. / Must be careful -- public toilets. / Stop shaking hands. / Common sense. / Stay away from fagots.

19. Don't Know

20. No Response

D. DERIVATION OF NEW VARIABLES

Q.82 - 83

Were derived from the sample frame and the corresponding questionnaire identification numbers to form the sample strata and community size.

Q.84 - 86,
87 - 89,
91 - 93

Were derived from the multiple mentions in Questions 2, 33 and 24 respectively.

Q.94 MARITAL STATUS BY CHILD
Was derived from Q.73 "Marital Status," and Q.74 "Number of Children" according to the following reference matrix.

	Q.74				
Q73	X	1	2	3	4
1	X	1	4	4	4
2	X	2	3	3	3
3	X	5	4	4	4

The resulting response categories were labelled as follows:

1. SINGLE NO CHILD
2. MARRIED/COMMON LAW NO CHILD
3. MARRIED/COMMON LAW WITH CHILD
4. SINGLE PARENT FAMILY
5. DIVORCED/SEPARATED/WIDOWED/NO CHILD

Q.95 EMPLOYED BY SEX

Was derived from

Q.81 Sex
Q.78 Employed
according to the following matrix

Q.81	Q.78:EMPLOYED 1	2
1	1	2
2	3	4

The resulting response categories were labelled as follows:

1. MALE EMPLOYED
2. MALE UNEMPLOYED
3. FEMALE EMPLOYED
4. FEMALE UNEMPLOYED

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The Acquired Immune Deficiency Syndrome is not as widespread in Nova Scotia as it is in some other places. But Nova Scotia is not isolated from the larger world, and AIDS is among us – a new and fatal syndrome for which there is now no known cure or vaccine. At this time, education and responsible behaviour are the only effective defences against AIDS.

AIDS has created an unprecedented series of challenges which test our values as individuals and as a society. AIDS challenges our sense of individual responsibility, our compassion, our sense of community and our honesty. To the extent that we meet these challenges successfully, we will develop a society which is more responsible, open, tolerant and kind.

Nova Scotia is a close-knit and caring community. The Nova Scotia Task Force on AIDS believes that as Nova Scotians come to understand the facts about AIDS and the suffering it causes, they will respond with the thoughtfulness and consideration which are the hallmark of our society, and do all they can to fight the spread of AIDS, help those who are stricken and protect the rights from which all of us benefit.